



## UWS Academic Portal

### Dementia in the Workplace

Tolson, Debbie; Ritchie, Louise; Danson, Mike; Banks, Pauline

Published: 01/01/2016

[Link to publication on the UWS Academic Portal](#)

#### *Citation for published version (APA):*

Tolson, D., Ritchie, L., Danson, M., & Banks, P. (2016). *Dementia in the Workplace: the potential for continued employment post diagnosis*. University of the West of Scotland.

#### **General rights**

Copyright and moral rights for the publications made accessible in the UWS Academic Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

#### **Take down policy**

If you believe that this document breaches copyright please contact [pure@uws.ac.uk](mailto:pure@uws.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.

---

# Dementia in the workplace

---

The potential for  
continued  
employment post  
diagnosis.

---

Prof Debbie Tolson  
Dr Louise Ritchie  
Prof Mike Danson  
Prof Pauline Banks

---

October 2015

---

## Contents

Acknowledgements.....	4
Abstract.....	4
1. Introduction .....	5
1.1 Background .....	5
1.2 Theoretical background .....	6
1.3 Aims and objectives .....	9
1.4 Project reference group.....	9
1.5 Project overview .....	9
2. Literature review.....	10
2.1 Search Strategy .....	10
<b>2.2 Search Results</b> .....	10
2.3 Literature review results .....	12
2.4 Literature review key findings .....	15
3. Key informant interviews.....	16
3.1 Key informant Methods.....	16
3.1.1 Recruitment and procedure.....	16
3.2.2 Data analysis .....	17
3.2 Key informant Participants .....	18
3.3 Key Informant Results.....	18
3.3.1 Theme 1 – Challenges of dementia in the workplace.....	18
3.3.1.1 Diagnosis .....	18
3.3.1.2 Complexities of each individual situation .....	19
3.3.1.3 Problems in the workplace .....	20
3.3.2 Theme 2 – Supporting people with dementia in the workplace .....	20
3.3.2.1 Support required.....	20
3.3.2.2 Dementia awareness training .....	22
3.2.2.3 Dementia as a disability .....	22
3.3 Key informants key findings.....	24
4. Case Studies .....	25
4.1 Case Studies Methods.....	25
4.1.1 Case study research design.....	25
4.1.2 Recruitment of case study participants .....	26
4.1.3 Recruitment .....	27

4.1.4 Ethical Approval .....	28
4.1.5 Materials and Procedure .....	28
4.1.6 Data analysis .....	29
4.2 Case study Participants .....	30
4.3 Cross case analysis .....	33
4.3.1 Theme 1 – Experiencing dementia in the workplace.....	34
4.3.2 Theme 2 – Supporting continued employment.....	40
4.3.3 Theme 3 – Work keeps me well.....	51
4.3.4 Theme 4 – Workplace perspectives .....	55
4.4 Case study key findings .....	59
5. Discussion.....	60
5.1 Strengths and limitations.....	61
5.2 Supporting continued employment post diagnosis.....	62
5.3 Impact of continued employment .....	64
5.4 Policy implications .....	66
5.5 Recommendations .....	68
5.6 Conclusion.....	69
6. How well were the objectives met?.....	70
7. Publications and dissemination .....	71
7.1 Publications.....	71
7.2 Conference presentations.....	71
7.3 Other dissemination .....	72
7.4 Media coverage.....	72
8. Any other output or impact from the project.....	73
9. Future plans .....	73
10. What was your experience of working with Research Network volunteers? .....	74
11. Lay Summary.....	75
<b>11.1 Introduction</b> .....	75
<b>11.2 Aims and objectives</b> .....	75
<b>11.3 Literature review</b> .....	76
<b>11.4 Key informant interviews</b> .....	76
<b>11.5 Case studies</b> .....	78
<b>11.6 Discussion</b> .....	80
12. References .....	82

13. Appendices.....	87
---------------------	----

## Acknowledgements

Thanks go to all of the participants in this study who so kindly gave their time and so openly shared their experiences as part of the research. This study would not have been possible without them. Thanks also go to all the organisations and individuals who supported development of the project and assisted with recruitment, including Alzheimer Scotland, the Scottish Dementia Clinical Research Network and members of the project reference group. In particular we wish to recognise the exceptional commitment and helpful contributions of the late Jonathan Kneeshaw to the project in his role of Alzheimer's Society Research Network Volunteer. Jonathan, along with his colleagues Kate MacGowan, and Lynne Chambers were instrumental in shaping the project and supporting the research team, thanks goes to all of them. Finally, thanks go to the Alzheimer's Society for funding the study, the belief in the study and commitment to the project was greatly appreciated.

## Abstract

Given the current emphasis on early diagnosis and the increase in state pension age across Europe it is likely that the number of people in employment when diagnosed with dementia will increase. To date, little attention has been paid to the issues surrounding continued employment for people with dementia. This project aimed to explore the employment-related experiences of people with dementia to assess the potential for continued employment. The project comprised three phases: a literature review, sixteen key informant interviews and finally, seventeen case studies of people with dementia who were in employment when they were diagnosed. Six papers were included in the integrative literature review, which highlighted the dearth of information in the area. The key informant interviews were carried out with a range of healthcare and employment professionals and identified the complexities of supporting dementia in the workplace, but also the range of support which may be available. Of the seventeen case studies included in the final phase, eight continued employment post diagnosis, highlighting that continued employment post diagnosis. A cross case analysis was carried out which highlighted the similarities and differences between the cases. The main findings were that while continued employment post diagnosis was possible, it was not the best option for everyone and could be complex to support. Factors such as the type of job, getting a timely diagnosis and organisational culture all had a role to play in supporting people with dementia to continue employment. This study was the first in Europe to fully explore the experiences of people with dementia in employment to develop an understanding of the level and type of support that may be required for a person of working age when they are diagnosed with dementia. Based on the findings reported, recommendations are made which aim to shape future research, and influence policy and practice for supporting people with dementia in their employment.

## 1. Introduction

This document reports on the findings of the Alzheimer's Society funded project 'Dementia in the Workplace: the potential for continued employment post diagnosis' which was carried out at the University of the West of Scotland and in partnership with Heriot-Watt University. The report is structured into five chapters, the first of which lays out the background to the project and the aims and objectives of the project. The subsequent chapters will address each of the five aims set out, chapter 2 presents the findings of the integrative literature review, chapter 3 presents the findings of the key informant interviews while chapter 4 will report the findings of the case studies and the thematic cross case analysis. The discussion in chapter 5 will bring the findings of these chapters together and will make recommendations for future research, and to influence policy and practice relating to the employment of people with dementia. Subsequent chapters will present additional information relating to the project, including the lay summary, the dissemination of the project and the appendices and references for the main report.

### 1.1 Background

A combination of the predicted reduction in the working age population, the increase in the 60+ population, and the current economic situation has prompted the UK Government to abolish the default retirement age of 65 and raise the age at which people receive the state pension to 66 for both men and women by 2020, eventually rising to 68 or 70 enabling people to work longer in order to accrue additional pension. Extending working life may bring financial benefits to individuals, as well as the economy and businesses which will benefit from a reduction in pension payments and have access to a skilled labour force (Brown, et al., 2008). However, an increase in the number of older people in employment is likely to have economic costs as well as economic benefits (Breachin, 2004). A systematic review carried out by Crawford et al (2010) identified a number of age-related physical and psychological changes which could impact on performance in the workplace. The authors suggested that employers would benefit from training for age management. Some employers have been found to hold negative attitudes towards older workers (Walker, 2006), attributing more positive work attitudes and superior job performance to their younger counterparts (Taylor & Walker, 1994). Work by the Chartered Institute of Personnel and Development (CIPD) in the UK found that management and fellow workers had difficulty accepting that older workers should be treated similarly to other staff; findings of a survey (CIPD, 2006) indicated that less than half those aged 65 or over received a formal annual appraisal compared to almost two thirds of all employees.

A recent study carried out by Danson and Gilmore (2012) explored the views of higher education institutions on the removal of the default retirement age. A small number of organisations discussed proactive change, such as guidance to managers based on ACAS advice; however the majority talked about changes they were planning to make in the future. While a variety of views were expressed, it was evident that the productivity and standards of work of older employees would come under closer scrutiny as organisations strive to ensure that all employees add value to the workplace. Union representatives highlighted the dangers of 'arbitrary performance measures' being used to undermine staff and to exit them from the organisation.

Increased labour market participation in later life will result in a higher number of people with long term conditions in employment and, while the impact of some long term conditions, particularly

those associated with physical impairments, can be reduced by use of assistive technology and/or a change in role, continued employment for people with cognitive impairments, for example dementia, stroke, or head injury poses specific difficulties for the individuals themselves and their employers. The Equality Act (2010) required employers to make 'reasonable adjustments' to support employees with a disability, typical adjustments may be made to the physical environment or the use of assistive technology. However; a reduction of duties, a change in working pattern or a system of quality checking may be more appropriate adjustments for a person with cognitive impairment.

Because dementia is typically associated with older age, limited attention has been paid to the potential for employment post diagnosis. Bentham and La Fontaine (2006), focusing on services for younger people with dementia in the UK, noted that it is not unusual for people with early symptoms to be made redundant or be dismissed for incompetence. They found that some younger people with dementia wished to remain in employment, and suggested that efforts should be made to persuade employers to support people to retain appropriate employment and/or to recognise dementia as a reason for early retirement so that pension rights and other benefits are not affected. Under UK social security regulations and eligibility criteria, a diagnosis of long term health problems/disability can be critical in securing welfare support and, if that has not been forthcoming or is delayed, employment can be essential to maintaining an income. However, receiving a diagnosis can take time.

In recent years there has been a growing awareness of the impact of dementia in the workplace. For example a review carried out by Alzheimer Australia (2007) reported that first symptoms of dementia often became apparent in the workplace, with decisions to leave employment being prompted by employers. A number of articles have highlighted the need for occupational health professionals to be aware of the problems and be proactive in helping people to gain a diagnosis and secure support to retain employment where possible (Chaston, 2010; Mason, 2008; Martin, 2009).

## **1.2 Theoretical background**

Compared with the notion that labour markets are competitive and open, many believe that institutions – occupations, firms, legislation, trades unions, etc., determine the ability of individual workers to enter and progress in their career or to suffer precarious and unstable employment. Therefore, the expectation from the literature is that the institutional context as well as the individual's human capital would influence the experiences of those being diagnosed with early onset dementia or memory problems. The labour market can be considered as being segmented into a Primary sector of well paid, secure jobs with possibilities for career progression and economic returns to investment in human capital (i.e. more experience, training, personal development leads to higher wages), and a Secondary sector of low paid (national minimum wage) insecure jobs where "the only nexus is cash" and better education, skills and experience do not result in improved employment (Piore and Doeringer, 1971).

Some (Edwards et al., 1975; Hudson, 2007) developed this framework to subdivide the Primary into Upper and Lower Primary sectors – where the former is characterised by professional skills that are enhanced throughout working life with promotion within the occupation based on rising experience and expertise. Positions in the Lower Primary are typically in one of the traditional skilled manual



trades, often employed in large firms or identifiable parts of their occupation with strong trades unions or trade associations; when in major plants, organisations or authorities skills may degrade as the worker becomes institutionalised by the specific demands of the particular labour process of the employer.

This segmentation into Upper Primary, Lower Primary and Secondary has parallels with the description of labour market structures as Guild – professional, high paid, secure jobs where the attachment is to the skill-based occupation and mobility is within the profession but often between employers; Manorial – based on apprenticeships or educational qualifications, well paid, secure, where the worker is recruited to and tends to remain with the same employer, progressing up the job ladder with that employer; and Unstructured – low paid, poor terms and conditions, no career ladder and so mobility to a similar post with another employer does not involve costs or loss of seniority (Kerr, 1977).

This brief review suggest that for those in Upper Primary- or Guild-type jobs, while they arguably had the best labour market positions initially, the deterioration in their human capital with the onset of dementia and the dependence of their employment on their own human capital could mean a significant risk of redundancy of skills and jobs. They would probably find no alternative employment available which would allow them to apply their degrading and disappearing human capital. For those with low skills in precarious and insecure jobs – Unstructured and Secondary – diagnosis would similarly result in job redundancy with great difficulties in securing any new contracts so that dependency on welfare benefits becomes the dominant destination. For those in Lower Primary or Manorial situations, employed in large organisations which can offer diverse job opportunities and well-defined employment rights with their internal labour markets, there might well be the potential for redeployment to less demanding jobs where their failing skills and declining human capital could still be accommodated.

Leon (1985) explored the factors that drive ‘status attainment, human capital, and labour market segmentation models’ and concluded that these explain much of the variance in pre- and post-retirement economic status. In identifying that crucial life-span characteristics and circumstances determine the developments of individuals paths, this offers an introduction into how to analyse the interacting dimensions of those with long-term illnesses in different contexts. Therefore, an area of interest in the case studies was to determine the post diagnosis experiences of different workers with an expectation that those with skills and qualifications in larger organisations would have better opportunities to continue in their existing workforces while the unskilled and those with high specific skills in smaller organisations or self-employment would be at greater risk of exclusion from the labour market..

Across the developed world, countries are facing both declining and ageing populations, and so are addressing the threats to their competitiveness by attracting more highly educated workers and by investing in human capital. As the population is still ageing, there are parallel concerns over the affordability of state support for the elderly, their roles in society and the economy (Bloom et al., 2010). Therefore states are also extending the length of the working life to recognise greater longevity and to help meet the social costs of an older population.

By 2000, the UN had concluded that potential support ratios (the dependency of those over a particular age on those of working age) could be maintained at current levels by increasing the upper limit of the working-age population to roughly 75 years of age (UN 2000). Many countries, including the UK, have been making strategic changes to the Statutory Retirement Age (abolished) and Statutory Pension Age (extended), therefore, to raise the levels of participation in the labour market by older workers (Brown et al., 2008; Danson and Gilmore, 2012). Although still at fairly low rates, formal work is becoming more common beyond the statutory pension age already and has risen from about 7.4% for men over-65 in the UK in 1994 to 13.5% in late 2014, with similar increases for women (ONS, 2015). Beyond this paid work, older people also play an important role in providing other services which, although unremunerated, may nevertheless be regarded as an essential element of the social capital of communities (Phillipson *et al.*, 1999). This includes domestic responsibilities (providers of care for children or disabled elderly partners) (Wheelock and Jones, 2002), or through active informal and formal community participation (in a whole range of community and group activities) and through sharing knowledge and learning (experience, skills, local knowledge) (Williams, 2003).

Multinational research by Fortuij et al. (2006) have challenged the idea of older adults as inactive and unproductive human beings and have highlight the productive non-paid contribution of older adults to local economies. Their study on the involvement of 50–90 year olds in daily activities and their satisfaction with these has revealed that in many cultures employment is seen as the most important form of productivity and being productive is often associated with being ‘functional’. While this reinforces the idea that later life is about not ‘working’, they emphasise that other non-paid activities – such as voluntary work, giving assistance to other people, and home maintenance and housekeeping, are crucial to individual well-being and self-worth, and to local economies. This and complementary work has demonstrated that staying active for longer and adopting an active lifestyle balanced between work, volunteering, leisure and volunteering promises better opportunities for healthy ageing. Strategies to promote an active and flexible lifestyle are being pursued to extend healthy life expectancy, and so extending the length of the working life is increasingly seen as a way to ease the transition to an economy where an ageing population is affordable (Walker, 2006). It follows that, for those who are unable to enjoy a long and healthy life and retirement, there is the risk of poverty and inequality to the detriment of all, as argued by Hawton et al. (2011).

Keeping those with early onset dementia, and other limiting long-term illnesses active in the labour market should be beneficial for both the individual, their families and indeed the economy (Brown et al., 2008), therefore, and exploring and understanding employer and co-workers’ attitudes to supporting this strategy is important (Loretto and White, 2006; Taylor and Walker, 1994).

Much of contemporary policy in health and social care advocates a focus on the person with dementia. Accordingly person centred practice has become the service mantra and a feature of national dementia strategies and action plans (Scottish Government 2013, Department of Health 2013). Descriptions of person centred approaches (McCormack 2004 ) highlight the importance of knowing the person in terms of who they are, their relationships with others and the contexts through which their personhood is articulated. In the case of an employee with a diagnosis, this reminds us of the interplay and interconnected of work and our understanding of self. Edvardsson et

al (2010) usefully elaborate the existential dimension of being person-centred, explaining this in terms of ‘promoting a continuation of self and normality’.

### **1.3 Aims and objectives**

The overall aim of this project was to explore the employment related experiences of people with dementia or MCI, and attitudes of employers and/or co-workers towards supporting people with dementia, in order to identify the potential for continued employment post diagnosis.

Five objectives arose from the study aim:

- 1) To assess the potential for continued employment for people with dementia or MCI post diagnosis
- 2) To ascertain how people with dementia or MCI cope in the workplace
- 3) To determine how employers manage challenges associated with employees who show signs of dementia/MCI
- 4) To ascertain the level of support that people with dementia or MCI require to retain employment, and whether employers and/or co-workers are able or willing to provide support of this nature
- 5) To inform public policy relating to the employment of people with progressive conditions

### **1.4 Project reference group**

A project reference group was set up at the beginning of the project in order to help shape and develop the project. Individuals from key organisations were invited to attend a series of meetings throughout the research period. An initial invitation letter was sent out to invite membership of the group along with an information leaflet about the project (appendix 13.1). The reference group had 20 members from varying backgrounds including, healthcare professionals, researchers, employment agencies, advocacy agencies and carers groups. The Alzheimer’s Society research network volunteers for the project were also members of the project reference group. The group met formally on two occasions, at the beginning of the project and then one year into the project with informal contact with members when required to assist with the progression of the project. For example, the reference group members assisted with the recruitment of key informant interviewees and participants for the case studies.

### **1.5 Project overview**

Each of these aims will be addressed in the remainder of this report. There were three main components to the study which will be reported on in the following chapters. Chapter 2 reports the findings from the literature review, chapter 3 will report on the findings of the key informant interviews and chapter 4 will report on the case studies of people with dementia who were in employment when they experienced the onset of the symptoms of dementia. The report will conclude with a discussion of the findings and make recommendations to inform policy, practice and future research in line with the fifth objective listed above.

## 2. Literature review

A literature review (Ritchie et al., 2015) (appendix 13.2) was carried out to inform the development of the project. The aim of the literature review was to establish, from a range of perspectives, the potential for continued employment post diagnosis for a person with dementia, and the nature of support that would enable/enables people with dementia or mild cognitive impairment (MCI) to retain employment. This in turn addresses the study objectives:

- 1) To assess the potential for continued employment for people with dementia or MCI post diagnosis
- 4) To ascertain the level of support that people with dementia or MCI require to retain employment, and whether employers and/or co-workers are able or willing to provide support of this nature

### 2.1 Search Strategy

An integrative review strategy was adopted to cover the diverse range of literature which may exist from a range of disciplines, including health, social sciences and business. Integrative reviews are the broadest type of research review method allowing for the simultaneous inclusion of experimental and non-experimental research in order to more fully understand a phenomenon (Whittemore and Knafl, 2005). They may combine data from theoretical as well as empirical literature, address a range of purposes, and have the potential to produce a comprehensive portrayal of complex concepts. An initial key word search was carried out on a range of databases as shown in Figure 2.1. Results were screened for relevance first by titles, then by abstracts and finally full papers where adequate information was not available from the titles or abstracts. Inclusion and exclusion criteria are shown in Figure 2.1.

### 2.2 Search Results

Two papers were identified which directly addressed the experiences of people with dementia in the workplace; three included employment of people with dementia in their outcomes. One paper was identified which examined employers' awareness of dementia in employment. Details of the six papers included in the review are summarised in Table 2.1. Each of these papers was assessed for relevance to the topic and methodological quality. Quality assessment was based on the development of a tool, influenced by the criteria set out by the Joanna Briggs Institute QARI and MASTARI tools<sup>1</sup>. As this review included both qualitative and quantitative research papers, the most appropriate appraisal tool was selected and accordingly a quality score calculated based on the percentage of satisfied criteria. Quality assessments were performed independently by two reviewers and compared to promote rigour. The quality scores (percentages) are shown in Table 1 to highlight distinctions in methodological quality. Due to the small number of papers identified, no paper was excluded on the basis of quality which ranged from 14% (low quality) to 80% (high quality). Following quality rating, information relating to the methodology and outcomes of each paper were extracted and thematically coded. Codes related to the focus of the paper (employer, colleagues or employees), information about the general experience of dementia in the workplace, first symptoms, and supports available and used.

---

<sup>1</sup> <http://joannabriggs.org/assets/docs/sumari/ReviewersManual-2011.pdf>

Figure 2.1 – Search strategy and output

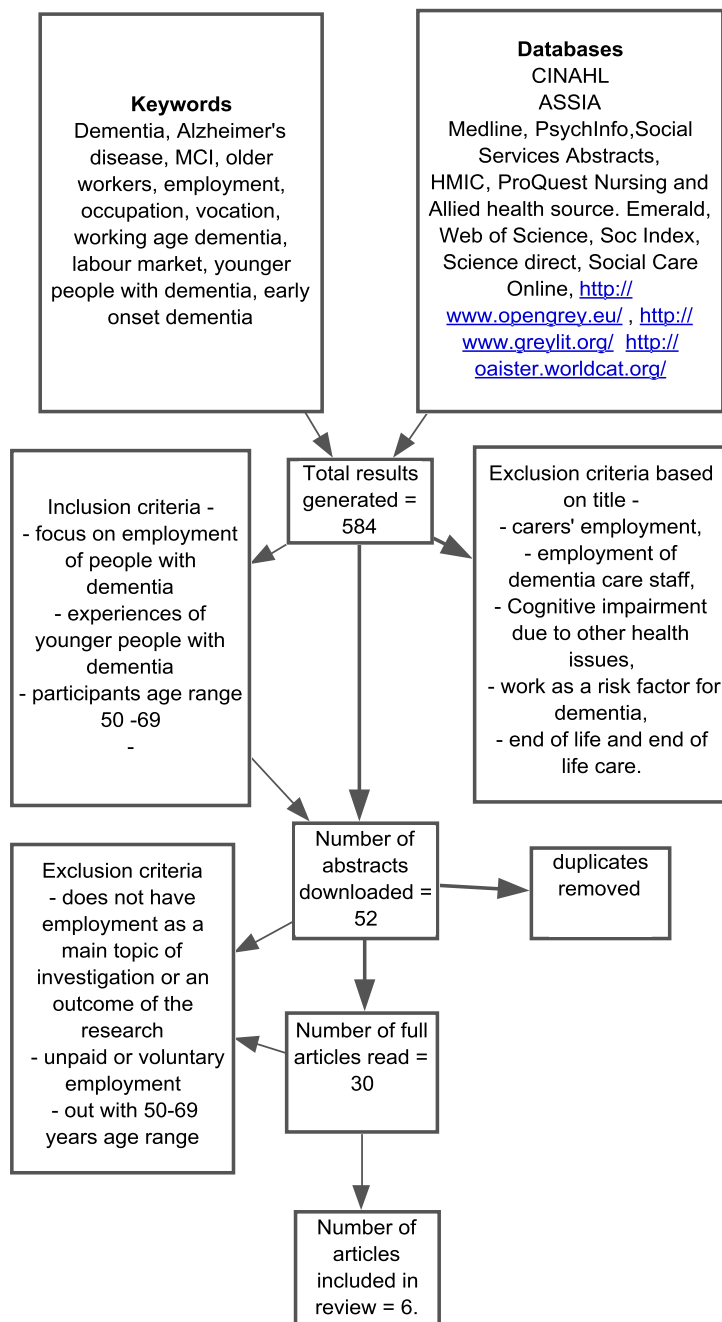


Table 2.1: Papers included in review

Author	Title	Aim	Methodology	Analysis
Chaplin and Davidson (2014)	What are the experiences of people with dementia in employment?	To uncover the experiences of people with dementia in employment	Interviews	IPA
Cox and Pardasani (2013)	Alzheimer's in the workplace: a challenge for social work.	To explore the views and experiences of HR professionals relating to dementia.	Online questionnaire	Percentages / grounded theory.
Harris and Keady (2009)	Selfhood in younger onset dementia	To examine the impact a diagnosis has on selfhood and identity.	Interviews	Grounded theory/ cross interview analysis
McGurk and Mueser (2006)	Strategies for coping with cognitive impairments of clients in supported employment	To evaluate the coping strategies used by employment specialists to support clients with cognitive impairments.	Questionnaire	Descriptive percentages
Ohman, Nygard and Borell (2001)	The vocational situation in cases of memory deficits or younger onset dementia	To describe how persons with memory deficits or younger onset dementia perceived and met their problems with particular relevance to their present and future vocational situation.	Interviews	Constant comparative approach
Pipon-Young, Lee, Jones and Guss (2011)	I'm not all gone, I can still speak: the experiences of younger people with dementia. An action research study.	To explore the experiences of younger people with dementia	Interviews/ Action research	Thematic analysis

## 2.3 Literature review results

Four of the six papers identified employment as a concern for people who were diagnosed with dementia at a younger age (<65 years). The exception to this was in research carried out by Pipon-Young *et al.* (2011). In this study participants reported no issues with employment or with retirement as a result of their diagnosis; however, all eight participants were female, in their 60s, and had left work for other reasons prior to diagnosis. In contrast, Harris and Keady (2009) categorised 'identity as a worker' as their first theme within their research on 'Selfhood in Younger Onset Dementia', which involved interviews with 23 younger people with dementia and 15 family

carers. The study found that employment status could be the first thing altered following diagnosis, having a negative impact on the person's sense of self.

Two papers looked directly at the experiences of people with dementia who had been, or were still, in employment with a diagnosis of dementia or memory problems. Ohman *et al.* (2001) interviewed nine people about their experiences of dementia or memory problems while still in work. They also interviewed workplace informants for six of the participants. More recently Chaplin and Davidson (2014) interviewed five people about their work-related experiences of dementia. A number of overlapping findings are discussed below.

#### *Impact of symptoms in the workplace*

Memory failures were the most commonly described initial symptoms by participants in both studies. However, memory problems were not the only symptom and not all participants experienced memory failures in the workplace. Other problematic symptoms included word-finding, learning new material, using technology, problems with visuo-spatial tasks such as filling in charts, and general issues with concentration and motivation. The participants in Ohman *et al.*'s study reported that these initial changes in the workplace diminished their confidence in their own ability, and increased stress and anxiety which placed additional pressure on their physical health and abilities. Whereas Chaplin and Davidson highlighted the participants' reluctance to acknowledge the signs of cognitive impairment, passing them off as personality traits or linking them to normal ageing: for example, poorer eyesight. These differing themes may reflect methodological differences rather than different experiences of the participants. However, what is common across both of the papers is that a crisis point was reached where participants realised they could no longer cope in the workplace and had to seek support.

#### *Coping strategies in the workplace*

All participants in the Ohman, *et al.* and the Chaplin and Davidson studies reported different strategies that they used to manage their symptoms in order to help them cover up symptoms or to cope with the extra pressures of the workplace. Examples of these are; writing notes and memos, spending more time planning and organising tasks, and making full use of a diary. However, it is unclear how useful these strategies may be, participants in the Ohman, *et al.* study did not find the strategies useful while the participants in Chaplin and Davidson's study found the strategies effective. Similar findings relating to the usefulness of coping strategies were found in a study involving employment specialists supporting people with cognitive impairments in the workplace (McGurk and Mueser, 2006). 50 employment specialists were then asked to indicate how often they used each strategy from a list of 76 coping strategies and to rate how useful they thought they were. The employment specialists most often recommended coping strategies for people with problem solving difficulties, followed by attention and memory problems. However, the coping strategies which were rated most effective were the strategies which addressed attention problems, while those designed for problem solving strategies were rated least effective. This suggests that, even if coping strategies are not thought to be effective, they are still frequently used.

### *Support in the workplace*

Both the Chaplin and Davidson and the Ohman, *et al.* papers discussed the issues that employers had when informed of an employee's difficulties. It should be noted, though, that in the Chaplin and Davidson study this is only from the perspective of the employee - no employer input was sought. This is reflected by the higher methodological quality score for the Ohman, *et al.* paper. A common finding was that employers appear to lack knowledge to enable them to support people with dementia or cognitive impairment in the workplace. In the Chaplin and Davidson study, participants reported that their employers offered no reasonable adjustments to support them to continue employment and that some employers implemented strategies which led to further confusion and distress for the employee. Employees were likely to be put on sick leave or have their employment terminated, either by being offered early retirement or being dismissed when they received their diagnosis. In the Ohman, *et al.* paper, there was evidence of employers trying to support people to stay in employment; however adaptations were often ill-informed resulting in further problems. For example, two participants were moved to less challenging jobs within the company. This did not have the desired effect as the employees experienced the same problems with learning new material and processes as they had in their previous roles.

### *Staff perceptions*

The Ohman *et al.* study benefits from having a workplace perspective as it provides a more balanced view of the situation, including how colleagues felt about supporting work colleagues with cognitive impairment. The workplace respondents were positive about wanting to support their colleague to stay in employment. However, they did note the difficulties in doing so including economic problems related to paying a full salary to someone who was unable to undertake all duties relating to a role, and the negative reaction observed from employees who had to take on additional duties to compensate. It was also interesting to note that while the participants reported having struggled at work for a long period of time, workplace respondents did not report noticing any differences in their colleague until much later.

A recent study carried out by Cox and Pardasani (2013) used an online survey to explore Human Resources (HR) professionals' awareness relating to dementia in the workplace for both carers of someone with dementia, and employees developing dementia. One hundred and three HR professionals responded (14.7%). Almost half the respondents (44%) stated they had direct experience of someone developing dementia in the workplace. There were a number of methodological issues with this paper which is highlighted by the very low quality score in table 1. These issues included a potential sample bias and an unclear use of 'valid percentages' rather than percentages based on the full sample. Despite these reservations, the study has been included as it was the first study to examine knowledge of employers. It also highlighted the phenomenon of people developing dementia in the workplace although it was unclear how regular an occurrence it was. Where the paper was more useful was in addressing the issues surrounding policy regarding dementia in the workplace - only 2% of those who answered this question stated that their organisation had a policy in place for dealing with an employee who developed cognitive impairment whilst in work. The online survey included a number of open questions which sought respondents' views and/or concerns about dealing with dementia in the workplace. Analysis revealed that HR professionals had concerns relating to making inappropriate decisions about the future of a worker;



other staff members also experienced increased anxiety and distress when watching a colleague struggling with their work tasks and witnessing their performance decline.

## **2.4 Literature review key findings**

### *Box 2.1 Literature review key findings*

- 1) Six research papers were included in the literature review, of which only two had a specific focus on the employment of people with dementia.
- 2) No previous research has identified the potential for continued employment post diagnosis, thus little is known about the nature of the supports required to enable a person with dementia to continue employment post diagnosis.

### **3. Key informant interviews**

The purpose of the key informant interviews was to explore the current environment for people with dementia in terms of employment policy for people with disabilities, the role of voluntary organisations, statutory agencies, employers' organisations, and trade unions. In terms of the overall study, the key informant interviews will address the following study objectives:

1. To assess the potential for continued employment for people with dementia or MCI post diagnosis
4. To ascertain the level of support that people with dementia or MCI require to retain employment, and whether employers and/or co-workers are able or willing to provide support of this nature

#### **3.1 Key informant Methods**

To gain an understanding of the issues surrounding dementia and employment and because little research has been undertaken in this area, a range of key informants believed likely to have some knowledge or expertise relating to the issue were invited to take part in an interview (Marshall, 1996). Their views are necessarily regarded as an informed guide to how people react to potential clients presenting with a diagnosis or displaying behaviours consistent with this condition. These representatives were interviewed for their informed views and opinions and therefore, with the exception of the one participant living with dementia, were not intended to offer the voice, views and opinions of people with dementia or MCI. As these informants were expected to have relatively limited experience of workers with this condition in employment, the exercise reported here was planned to be instrumental in contextualising and informing the subsequent primary research. The aim here was to gain an insight into the understanding and attitudes of those in key agencies and occupations who might deal with workers presenting with the condition.

##### **3.1.1 Recruitment and procedure**

Potential key informants were identified by the research team and the project reference group members based on previous contacts and organisations with relevant expertise. Information about the project was sent by post and email to those identified with a letter inviting them to take part in an interview (appendix 13.3). One member of the research team then telephoned within the following week to answer any questions about the project and to ascertain whether they were willing to take part in the study. Key informant consent forms can be found in appendix 13.3.

Interview schedules were developed for each key informant based on their area of expertise; however, all interviews covered the following topics with the emphasis changing according to the role of the interviewee: (1) Role of participant; (2) Knowledge relating to the impact of age related long-term conditions on employment; (3) Specific knowledge relating to dementia or MCI including personal experience from the workplace or family/friends; (4) Knowledge relating to employment policy for people disabilities in general and how that relates to people with dementia ; (5) Other policies including dementia strategy etc.; (6) Views relating to supporting people with dementia or MCI in the workplace.

### 3.2.2 Data analysis

All interviews were recorded and transcribed for analysis. A thematic analysis of the data (Braun and Clark, 2006) was carried out using QSRNivo software. Following an initial familiarisation of the data, initial codes were generated and grouped into themes. In order to promote rigour, two members of the research team were involved in an iterative process of checking, refining and defining themes until a clear and coherent representation of the data was developed.

**Table 3.1:** Role of key informant interview participants

No.	Role	Mode of interview	Expertise
1	Senior Civil Servants (Scottish Government)(2)	Face to face	Government policy relating to dementia
2	Consultant in Old Age psychiatry.	Face to face	Dementia
3	Depute director of Human Resources	Face to face	Employment policy
4	Senior Nurse, Younger Adults with Dementia.	Face to face	Early onset dementia, supporting people to continue working
5	Consultant Clinical Neuropsychologist. (2)	Face to face	Dementia
6	AHP Lead for Vocational rehabilitation.	Face to face	Mental health vocational rehabilitation.
7	Consultant in Old Age Psychiatry.	Face to face	Dementia, patients who have been/are in employment.
8	Consultant Psychiatrist.	Telephone	Early onset dementia, patients who have been/are in employment.
9	Access to Work advisor, Department of Work & Pensions	Telephone	Disability and employment
10	Project Manager at Healthy Working Lives.	Face to face	Employer support
11	General Practitioner (GP)	Telephone	General health
12	Alzheimer Scotland Link worker	Face to face	Dementia, supporting people to continue working.
13	Person with Dementia	Face to face	Experience of being in employment when diagnosed with dementia.
14	Trade Union Representatives(2)	Face to face	Employee support and disability specialist.
15	Senior Disability Manager	Telephone	Disability and employment.
16	Head of Human Resources	Telephone	Employment policy

## 3.2 Key Informant Participants

Nineteen participants including health professionals who work closely with people with dementia, human resources professionals and employment specialists took part in an interview (Table 3.1). One key informant (no. 13) was a person with dementia who had experienced the onset of dementia whilst in employment and, although no longer in paid employment (and therefore not eligible for inclusion in the case studies), continued to work in a number of relevant voluntary roles. Of the twenty potential key informants identified, sixteen agreed to participate and interviews were carried out. On three occasions the identified key informant invited a colleague to the interview, resulting in a total of nineteen interviewees.

## 3.3 Key Informant Results

Thematic analysis of interview transcripts resulted in the formation of two overall themes: (1) challenges of dementia in the labour market and (2) support for dementia in the labour market, each containing subthemes which are outlined below.

### 3.3.1 Theme 1 – Challenges of dementia in the workplace

Participants spoke of a number of challenges which may be presented when a person begins to experience the symptoms of dementia in the labour market and is subsequently diagnosed.

#### 3.3.1.1 Diagnosis

Participants confirmed that getting a diagnosis of dementia at a younger age is not a straightforward process, acknowledging that the time this takes can be quite prolonged, however there is a great deal of variability in diagnosis times.

*I think in the UK that the evidence is there's something like a 3-4 year wait from initial being seen to, to getting a diagnosis. (KI10: Psychiatry)*

The interviews uncovered a number of issues which may contribute to a delay in a person with dementia gaining a diagnosis. First, there can be delays in referrals to secondary care. GPs are unlikely to refer people at first signs of symptoms, which may result in repeated appointments at the GP over a period of months before being referred.

*Sometimes I tend to just reassure them if I think well really I'm not convinced there's all that much going on with their general chat, and maybe they're just not concentrating some of the time (KI13: GP)*

Secondly, dementia is often not the first diagnosis considered when a younger person attends the doctor with memory problems. People concerned about their memories are often treated for depression, anxiety, or other mental health problems before dementia is considered and it is sometimes a process of elimination to reach a correct diagnosis.

*Somebody can be treated, for example, with depression for many months before people realise it's not, it's a bit more than that. (KI05: Nursing, Younger Adults with Dementia)*

Also, certain types of dementia (e.g. fronto-temporal) are more common in younger people who may present with different symptoms from the memory problems typically associated with Alzheimer's disease.

*I think it takes a lot longer because people just aren't aware of it or looked into fronto-temporal dementias. It tends to just come across as people being a bit more agitated or a bit more angry, loses some of their social graces. So it's subtler changes (KI07: Clinical Neuropsychology)*

Further, people with memory problems often forget to attend appointments which may add time onto the diagnosis process by having to reschedule appointments.

*Sometimes it could even be longer, because people have memory difficulties and they forget appointments, they don't turn up at appointments. (KI05: Nursing, Younger Adults with Dementia)*

Finally, the majority of tests of cognitive functioning for dementia are designed for an older population and may not be appropriate for younger people.

*Well in their fifties, most of the tests that we use are really standard for people who are over sixty-five... obviously the more over sixty-five then the more likely, well to a certain extent. When you get to ninety, the tests run into other problems.... (KI09: Old Age Psychiatry)*

It was thought that all of these issues have an impact on people's working lives as the longer it takes to receive a diagnosis, the harder it will be for them to get support in the workplace and the chances of them not being able to continue working will increase.

*The problem being that if someone is in employment, you know.... if it's a lengthy process then (yeah) it's a long time to try and support somebody (KI05: Nursing, Younger Adults with Dementia)*

However, one participant highlighted that support should not be dependent on having a diagnosis, rather that support should begin in the workplace at the point the employee is identified as struggling:

*One of the key messages is don't get hung up on diagnosis. We, you can't expect line managers, HR professionals to be doctors. It's not their job to diagnose. Their job is to identify the barriers and help remove the barriers. (KI18 Senior Disability Manager)*

### **3.3.1.2 Complexities of each individual situation**

Participants identified a number of factors which need to be considered when assessing the support that might be required for continued employment post-diagnosis. These included the type of employment; for example, some jobs would have health and safety implications or involve crucial decision making which could influence the overall running of the organisation or impact other employees; it was thought that someone with cognitive impairment may not be able to do this.

*It depends a lot on the job, so what you would have to do really is look at the job, look at the demands of the job and then look at the person's areas of weakness and try to come up with some kind of strategies they can use to compensate for it and I suppose there are some jobs that you might not think are particularly high powered jobs, but I mean if you're a secretary and you had memory problems that would be real difficult too. (KI07: Clinical Neuropsychology)*

The stage of dementia and the importance of early diagnosis were also believed to determine their potential for continuing employment. Participants indicated that being diagnosed at an early stage

might increase the probability of someone with dementia receiving support required to stay in employment.

*Well again it all depends at what stage that they get diagnosed. For many individuals then, you know, they are quite able and capable of working and particularly if they've got support. (KI10: Psychiatry)*

Finally, the work environment, including attitudes of co-workers, management and organisational policies were thought to be important in providing assistance for the person with dementia to continue employment. Colleagues could also be crucial in helping to monitor the situation and feedback to supervisors if they feel the person with dementia may be struggling.

*If they're accommodated still within the team who know them well and they're willing to support them for that while then that often seems to be quite supportive (KI10: Psychiatry)*

An additional challenge identified related to the amount of insight a person with dementia has into their difficulties. If someone doesn't have a great deal of insight, it may prove difficult to implement any supports as the person will not be aware that they have a problem, creating a difficult situation for their employer and colleagues.

*If that person isn't aware of any deficits or difficulties being made, it's, it's quite a tricky thing to try and redress. (KI07: Clinical Neuropsychology)*

### **3.3.1.3 Problems in the workplace**

The psychological trauma or emotional response associated with receiving a diagnosis of dementia at an early age was highlighted as a factor which could cause problems in the workplace. The stress of underperforming at work and having to accept support in the workplace may be a significant adjustment for the person and have a further negative impact on their employment.

*Making those adjustments, well nobody really expects they'll have to make, and perhaps are making them at an earlier stage in life is more psychologically traumatic. (KI07: Clinical Neuropsychology)*

Stigma relating to dementia was discussed as a potential problem to be addressed in the workplace, as has happened with other mental health problems. This may make a person with dementia reluctant to disclose their diagnosis to their employer.

*Given the fear and the stigma that there is around dementia it's highly likely, [that people won't disclose their diagnosis] but again that puts it into the same kind of camp as mental health conditions. (KI18: Senior Disability Manager)*

It was thought that people with dementia may attempt to cover up their symptoms in the workplace to counteract this.

## **3.3.2 Theme 2 – Supporting people with dementia in the workplace**

### **3.3.2.1 Support required**

It was agreed that possibly the most important asset to enable someone with dementia to stay in employment post-diagnosis would be a good support network including a supportive employer,

colleagues with a good attitude, trade unions, support from family and health professionals as well as support from peers in support groups or dedicated drop-in centres (e.g. dementia cafés).

*I do need the support in this of my team, like particularly the secretary..... so I write my own agenda and but we usually have a meeting beforehand and we go through exactly how we're going to play the meeting .... (KI15: Person with Dementia)*

However, when this support network is not available it can contribute to failings in the workplace, resulting in a loss of confidence in the person with dementia which may lead to them leaving work sooner than anticipated.

*We've seen other examples where they have been poorly supported ..... someone who appeared to be very poorly supported by their staff group. (KI10: Psychiatry)*

From a practical point of view, participants felt that coping strategies such as using a calendar, diary or keeping a notepad and pen close to hand may be useful to support continued employment. Other suggestions at work included adapting the person's role to include reduced responsibilities and reduced or flexible hours.

*They can do perhaps a less pressured or less frontline role that if they're accommodated still within the team who know them well. (KI10: Psychiatry)*

However, it was noted that this may be difficult to manage in a number of situations, for example someone who was self-employed or a lone worker.

It was recognised that dealing with dementia in the workplace would be difficult for employers as well as the people with dementia. It was considered easier for larger employers to support those with disabilities due to their internal occupational health and human resources departments, although in smaller organisations people tend to be better known and so can also be well supported through that network. Overall, it was argued that employers tend to differ greatly with how to support people with disabilities in the workplace.

*In large organisations that infrastructure's there to be able to support and do that type of work..... Smaller employers tend to have been much more supportive environments because people are known better. (KI12: Healthy Working Lives)*

Participants acknowledged the difficulties that employers could face and suggested that they required additional support than they currently have if they are to support employees with dementia to continue employment. The participants highlighted that there are many strands of support available to people with dementia and their employees who, although not specialised in dementia, are specialists in supporting people with disabilities to retain and gain employment. These include the government schemes to help fund disabled workers remain in or return to work and their employers with extra costs within the workplace, such as the Access to Work scheme, Working Health Services, vocational rehabilitation services and trade unions.

*So my job is to support them, to look at, you know, what are the reasonable adjustments which will support them, to maintain their role. And I might engage with employers or with employability agencies in order to help them to do that, or with other kinds of services; DWP, Access to Work, all those kind of things. (KI08: AHP Vocational Rehabilitation)*

Whilst there are similarities to supporting any other disability in the workplace, dementia is something that the majority of employers know very little about and have not previously considered as an employment-related issue.

Support would also be required in situations where continued employment is no longer a viable option. Employers need support in how to address this in an appropriate manner with their employee as previous experience of the participants has shown this has not been managed well.

*We also seen one or two who have been pushed out pretty quickly I have to say. (KI10: Psychiatry)*

Support for the employee is also required when leaving work, as there are many financial and social implications associated with leaving the labour market prematurely.

*It's not going to have been part of the plan that they would stop working when they were 50, for instance and often their partner still has to work but then they're concerned about what's going to happen in the future, are they going to have to give up work to look after them, how are they going to manage financially. (KI14: AS Link Worker)*

### 3.3.2.2 Dementia awareness training

It was suggested that some form of dementia-awareness training would be advantageous for an organisation supporting an employee with dementia. This would help to increase the understanding of dementia and how best to support a colleague with dementia within the wider staff team.

*I'm guessing a lot of employers don't know too much about dementia so maybe that kind of side of thing would be helpful. That's one that kind of springs to mind immediately that's fairly straightforward to do. (KI03: Old Age Psychiatry)*

Some workplaces have attempted to overcome this by providing dementia-awareness training, however a lot of this focuses on dealing with customers with dementia rather than colleagues or employees with dementia; nevertheless, this knowledge could be transferable to dealing with colleagues.

*[Staff] are better able to understand the impact of dementia in their dealings with that customer or their carer and they also have more confidence in being able to respond to that customer or the carer in an appropriate way.....So at a simplistic level I would say we would do exactly the same thing for a colleague who develops dementia. (KI18: Senior Disability Manager)*

### 3.2.2.3 Dementia as a disability

Although none of the employment related participants had direct experience of dementia in the workplace, they all agreed that if faced with it, the most appropriate approach would be to consider it in the same way as any other disability within the workplace. However, there were concerns about how to identify someone with dementia in the workplace to ensure they are not inappropriately subjected to performance review or misconduct procedures when the underlying cause is not identified.

*How would you recognise if it wasn't just a lack of concentration or a forgetfulness that isn't illness related you know, we've got no way of distinguishing that today? (KI19: Head of Human Resources)*



There was some disagreement between participants about how an employee who was developing dementia would be identified in the workplace. From an HR perspective, it was thought that performance review policies would pick up on an employee who was struggling to perform their duties.

*We have got a performance improvement policy; we shouldn't be using discipline for performance issues (KI04: Human Resources)*

Such policies detail procedures that 'should' be carried out; however, not all organisations have structured HR departments and/or formal appraisal systems. Similarly, participants from a healthcare background noted that in practice this was not the common route to identifying difficulties. It was thought that it was more of an informal warning system between colleagues and line managers, who noticed subtle changes in performance. However, this informal system would be dependent on the relationship between colleagues and would be unlikely to result in measures being put in place to support or improve the person's performance.

*It would be their kind of supervisor who they would kind of chat to saying "you know, I'm," you know, either "I feel I'm struggling" or the supervisor would say "you know, look this is the third time this week you've asked me about this and you've been doing this for years", you know, "what's going on", kind of thing. So it was these kinds of triggers that would bring attention. (KI09: Old Age Psychiatry)*

The Equality Act 2010 considers dementia as a disability which would require employers to provide reasonable adjustments to the workplace to enable employees to continue working. This highlights that employers have to consider whether a person with dementia can continue working in some capacity and provide reasonable adjustments to allow them to do so. Given the current lack of experience and understanding of the impact of dementia in the workplace, it was recognised that creating and managing reasonable adjustments could be a difficult process. The factors identified above such as the support network, stage of dementia and insight the employee has to their symptoms would also determine how successful any adjustment would be.

*I think it would be complex to manage. Reasonable adjustments generally are, and they are very subjective, and they rely on the goodwill of the managers and the colleagues around the person too. (KI04: Human Resources)*

Overall, from the participants interviewed, it is clear that there is a lack of knowledge and understanding around the nature of supports required for a person with dementia to continue in the labour market after diagnosis. It is clearly a complex issue, however basic principles of support need to be developed to complement and inform the disability support services available.

### 3.3 Key informants key findings

#### Box 2.1 Key informants key findings

- 1) The key informants from a healthcare background had more awareness of the issues surrounding dementia in the workplace than those from an employment background.
- 2) Supporting dementia in the workplace may be possible; however, each person with dementia will require different levels of support depending on the individual complexities of their situation.
- 3) There are a range of supports available to support people with disabilities continue or enter the labour market which could be adapted for use with people with dementia, however, to do this dementia must be conceptualised as a disability.

## 4. Case Studies

The purpose of carrying out case studies of people with dementia who were in employment when they experienced the onset of their symptoms of dementia was to explore the lived experience of developing dementia whilst still active in the labour market. The case study approach allows the experience to be examined in depth, and by the inclusion of other informants, from the perspectives of those who were involved in the supporting the individual. This gives both an in-depth account of the lived experience as well as the alternative views and attitudes of the situation from family members and workplace representatives. With this in mind, the case studies addressed the first four of the study objectives as outlined below:

- 1) To assess the potential for continued employment for people with dementia or MCI post diagnosis
- 2) To ascertain how people with dementia or MCI cope in the workplace
- 3) To determine how employers manage challenges associated with employees who show signs of dementia/MCI
- 4) To ascertain the level of support that people with dementia or MCI require to retain employment, and whether employers and/or co-workers are able or willing to provide support of this nature

### 4.1 Case Studies Methods

#### 4.1.1 Case study research design

There has been increased interest in non-experimental case study research over the past two decades (e.g., Stark & Strohschnieder, 2010; Crowe et al., 2011; Hellstrom et al., 2005). The use of case studies is an 'approach' rather than a method, which has been found to be useful when exploring significant incidents or events in people's lives. Case study research has been defined as a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within a real life context using multiple sources of evidence (Robson, 1993; Yin, 2009). The approach enables researchers to employ a range of methods to explore a specific incident or event in context, taking cognisance of significant players as well as the physical environment. In the proposed study the phenomenon of interest is the convergence of dementia or MCI and extended working life. Because dementia may impact on an individual's ability to give an account of their experiences in the workplace, for example some participants will have had greater insight into their difficulties at work than others, and ability to recall details may be impaired, case study research is particularly appropriate, allowing events and perceptions to be explored through a variety of lenses (Baxter & Jack, 2008). The ability to explore the same events and time period with a range of informants will contribute to the triangulation process. The number of cases studied ranges from intensive study of a few cases to less intensive study of many cases. While a single case study enables detailed exploration and analysis of information relating to one case, the use of more than one case allows cross case comparisons and the identification of themes across cases (Burns, 2010; Walshe, 2011). It was thought that the inclusion of between 15 to 20 case studies would achieve data saturation

#### 4.1.2 Recruitment of case study participants

Each case study is based around an individual aged between 50 and 69 who has a diagnosis of dementia or MCI and is in paid employment, or has left within the previous eighteen months. Case study information will be derived from a number of informants including family members, key individuals from participants' current or previous workplace, NHS, local authority or third sector staff, or other individuals identified. The inclusion criteria for case study participants were:

##### People with dementia

- Aged 50-69
- Diagnosis of dementia or MCI and aware of diagnosis
- Employed, self-employed, or stopped paid work within the previous 18 months
- People with alcohol related dementia must have a recent record of stable employment
- Be willing to identify additional case study participants
- Understand what taking part in the project would involve and give consent

The recruitment of additional case study participants was guided by the person with dementia. They were asked to nominate additional participants to inform the case study based on the following criteria:

##### Other participants

- Key informants from participants' current or previous workplace, family members, NHS, local authority or third sector staff
- Knowledge of participants' work related experiences

##### 4.1.2.1 Rationale for inclusion criteria

The inclusion of people with diagnosis of dementia as well as those with MCI is based on discussions with healthcare professionals at the planning stages. Although MCI is not an ideal predictor, this strategy is used in clinical trials focusing on the prevention or delay of onset of dementia (Garland et al., 2009) and people with MCI have been found to be more likely to progress to dementia compared to healthy controls (e.g. Brooks & Loewenstein, 2010; Haroutuntan et al., 2009). Discussions with people with dementia consulted while developing the research indicated that there was a window of opportunity for recruitment, 6-24 months following diagnosis/job loss. Those consulted indicated that they felt things had changed and they had moved on two years after leaving employment, so the decision was taken to recruit people who had left employment no more than 18 months previously. The decision to include people aged 50-69 is based on our desire to include people who are approaching state pension age, but may still wish paid employment. In the past women aged 60+ and men aged 65+ would receive the state retirement pension. Recent changes mean that people who would previously have been labelled as 'retired' will be 'unemployed' if they lose their job. Data from the Labour Force Survey are typically broken down into groups, with 50+ being one category; the questions asked allow people to be classified as economically active or inactive, all economically inactive people over 69 years of age are classified as retired (Office for National Statistics, 2011).

The inclusion of family members served two purposes. From the perspective of triangulation, interviews with family members will explore their views relating to the potential for their relative to continue, or to have continued paid employment after diagnosis. Their understanding based on knowledge gained prior to and around the time of diagnosis will be compared to the reports derived from the person with dementia and other case study informants, allowing the 'situation' to be viewed through different lenses. The second reason for including family members (where available) is that family members, who may or may not see themselves as carers, may feel protective of someone who has recently received a diagnosis of dementia; thus their inclusion in the initial recruitment and information giving meeting will recognise their position and role.

Finally, the inclusion of workplace informants served to further strengthen the triangulation by providing views relating to how the person with dementia functioned in the workplace and the impact that has on colleagues and work practices. While, family members and the person with dementia may provide information relating to this, previous research has shown that workplace informant views can vary greatly from the person experiencing the problems in terms of when they notice a change in performance and the perceived support they receive (Ohman et al. 2001).

#### **4.1.3 Recruitment**

Recruitment of case study participants sought to cover a range of scenarios including type of dementia, gender balance, age range (50-69), socioeconomic status, nature of employment, experience of leaving work where applicable, and family make-up using purposive sampling. Initially, two recruitment strategies were employed. Firstly, the Scottish Dementia Clinical Research Network supported the study by producing a list of potential participants who met the criteria of diagnosis and age who were already on the register. The list contained 62 people, an introductory letter was sent with the inclusion criteria followed up by a phone call to ascertain whether the person was suitable for the research and if they wanted more information. The second recruitment method was direct referrals from healthcare professionals. This began with a few key members of the reference group and as the project advanced the healthcare contacts increased through arranged talks and meeting at conferences. Healthcare professionals were given the inclusion criteria and basic information about the study to help them identify patients who were suitable for the study (appendix 13.7). They then passed on the information to the participants and if they were willing to participate they would ask permission to pass contact details on to the research team who would then contact them directly. This method had advantages as the healthcare professional was able to identify people who were at a stage where they were able to participate in research without it causing them additional distress. For example, they wouldn't refer a person who was going through a dispute with their work or was still coming to terms with their diagnosis.

As the project progressed it was noted that the initial methods were mostly successful at recruiting participants from Scotland as they rely mostly on local contacts. Reflecting on this, an amendment was made to the West of Scotland ethics committee, to adapt the recruitment procedure to allow for advertising for participants using media and social media outlets. Working with the Alzheimer's Society, posts about the research were put on Facebook, member forums and in the Living with Dementia magazine with a link to an online form to note interest in the study. When a note of interest was received, a member of the research team contacted the participants, either by email or post with an introductory letter and the participant information sheet. This was then followed up by

a telephone call a week later to find out if they were interested in participating in the study. This gave our sample a more diverse geographical spread, with participants in Scotland and England.

#### **4.1.4 Ethical Approval**

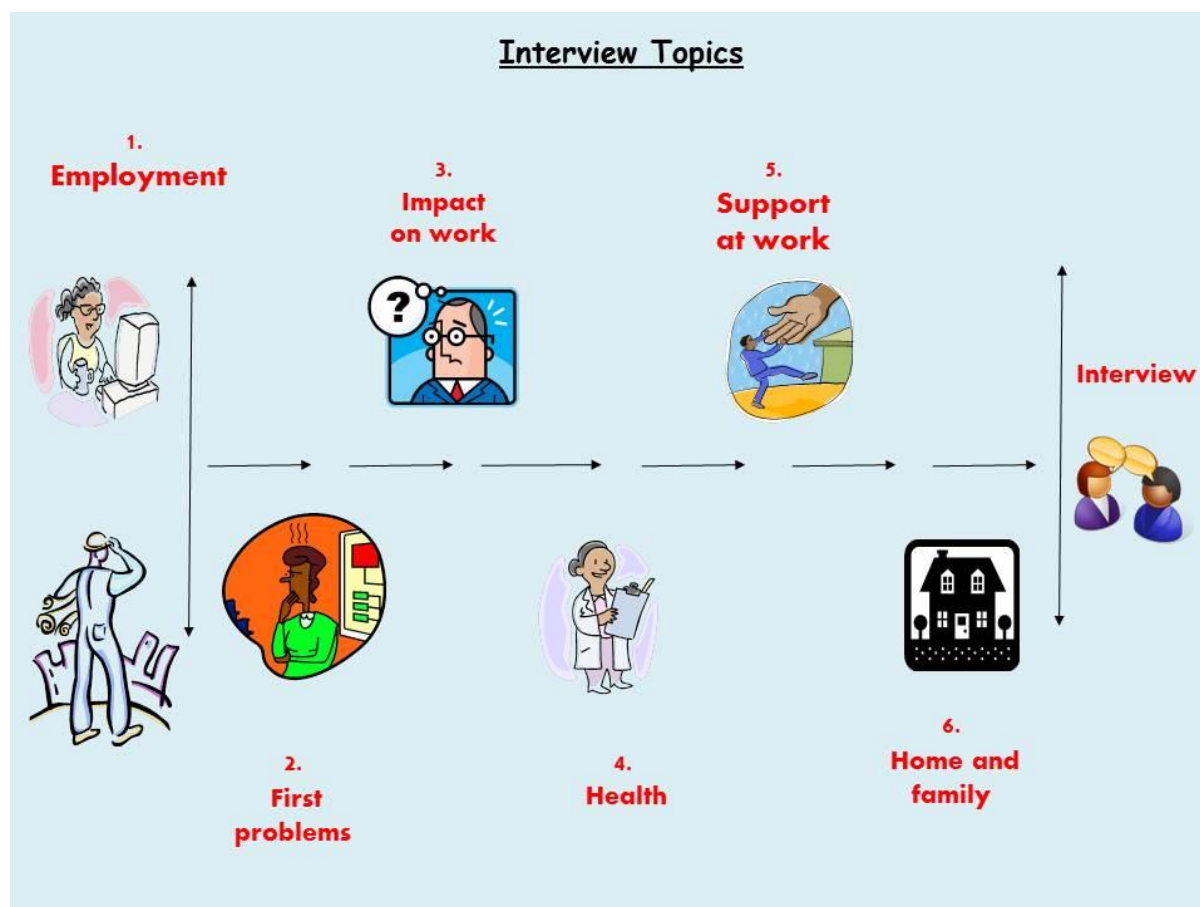
Ethical approval for this study was granted by the NHS West of Scotland Research Ethics Service (appendix 13.4). The main ethical issue that was addressed was regarding confidentiality of information during interviews with employers and/or colleagues. The main concern being that they may disclose information relating to the participants' employment which the participant was not aware of that the researchers may then report back to the participant. This was addressed by introducing the procedure that the workplace interviews would be completed only after all participant and family interviews were completed to reduce the risk of confidential information being passed back to the participant through the researcher. Informed consent was sought from each participant in the case studies. For the person with dementia, information was given in two stages; firstly, to allow them to express interest in the study and secondly for them to consent to participate in an interview. Participants were also invited to meet with or have an informal telephone discussion about the research with a member of the research team before they gave consent to participate. Information sheets and consent forms developed for each case study participant and can be found in appendix 13.5. A form for identification of workplace participants was given to the person with dementia following their interview which can be found in appendix 13.6.

#### **4.1.5 Materials and Procedure**

Data collection involved loosely structured interviews with the person with dementia or MCI, family members, key informant/s from the workplace, and other relevant players. Interviews with participants with dementia or MCI utilised research tools including visual or text prompts to facilitate discussion. Because each case study is different, interviews were based around topics rather than an interview schedule. Figure 4.1 shows the tool developed to facilitate the interviews of the person with dementia and the family member. This 'timeline' is based on a combination of LifeGrid and Timeline methods (Berney & Blane, 2003; Adriansen, 2012), both of which have been found to be useful when gathering retrospective data. It has been found that it is useful to have some form of reference when carrying out interviews, it allows you to bring participants back to previous issues and also allows them to have an idea of what will be coming next and makes it more of a 'shared experience'.

It was initially planned that the interviews with the person with dementia and their family member would be conducted separately. However in a number of the case studies, the interview with the person with dementia and their family member was conducted together (case studies 4, 5, 6, 10, 15, 16 and 17). There were a few reasons for this, mainly because the person with dementia did not feel comfortable talking to the researchers alone and requested their family member stay to support them. In these cases, the family member generally started the interview and when the participant felt comfortable they joined in and took the lead on explaining the work situation, with their family member providing specific bits of information or an additional perspective on what was said. Secondly, in two cases, the person's dementia had progressed and they were unable to communicate. In these cases, their spouse told the story of what had happened with their employment and the person with dementia corroborated this and gave additional information when they could, such as how much they enjoyed working or anecdotes about their friends at work.

Figure 4.1 Interview topic timeline



Conducting interviews jointly means that the version of events presented is jointly constructed between the participant and their family member, and not individual perceptions of the employment situation. However, it was important to include as much as possible the experiences of the person with dementia and allowing flexibility in the interview set up allowed this to happen.

#### 4.1.6 Data analysis

A thematic analysis was carried out of the case study data following Braun and Clarke's (2006) six phases of thematic analysis. Initially, interview transcripts and supporting documents were read and notes were taken on prominent codes from each one. This was then used to develop a coding schedule to be used to code all of the case study transcripts. To promote rigour, all members of the research team were involved in the coding of transcripts to check there was agreement in the codes being used. Each case study was coded separately and a report of the case study was produced. This included a detailed description of the case study, demographic details and notes on the emerging themes from that case study. The coding schedule was continually refined throughout the process of coding, and previous case studies were revisited to check for the new codes in a cyclical process. When all of the coding was completed, the cross case analysis began. The focus of this was to identify the similarities and differences between cases which were explored with a view to identifying the challenges faced by people with dementia and key individuals in their workplaces. The research team worked together analysing the codes and emerging themes from each case study

with reference to key differences such as job type, employment status and gender. From this, four general themes were identified which are reported in chapter 4.

## 4.2 Case study Participants

The recruitment procedures outlined above, in combination with two self-referrals to the project resulted in 17 case study participants being recruited. Full detailed descriptions of each case study can be found in appendix 13.7. All participants were given a pseudonym to preserve anonymity.

In line with the aims set out for recruitment the case studies represent a wide range of scenarios with regards type of dementia, gender balance, age range (50-66), nature of employment, and experience of leaving work where applicable, as shown in table 4.1 below. Of the seventeen case studies, 8 participants continued employment post diagnosis (although 3 of these had subsequently left employment at the time of their interview).

As discussed above, case study participants were asked to nominate other participants to build their case study, normally a family member and a workplace representative. The number of participants in each case study ranged from 2-6 and three case study participants provided supporting documents related to their employment. Table 4.2 below shows the additional participants in each case study and their relationship to the participant. Only one participant (case study 14) did not feel comfortable nominating a family member or a workplace informant to participate and so nominated their psychologist to take part in an interview. Other participants nominated more than one family member or workplace representative. In other cases, while the participant nominated a workplace representative, they did not respond to invitations to participate in the study.



*Table 4.1 – overview of case study participants<sup>2</sup>*

No.	Name	Occupation	Age	Gender	Diagnosis	Date of diagnosis	Continued employment post diagnosis?	Recruitment method
1	John	College Lecturer	56	Male	Frontotemporal dementia	Retired	No	Direct contact
2	Joe	Handy man	53	Male	Mild cognitive impairment	Employed	Yes	Healthcare referral
3	Michael	HGV driver	50	Male	Frontotemporal dementia	Retired	No	Healthcare referral
4	Jim	Electrical Engineer	66	Male	Alzheimer's disease	Retired	No	SDCRN
5	Paul	Council Officer	62	Male	Alzheimer's disease	Retired	Yes	Healthcare referral
6	Jack	Telephone Engineer	54	Male	Frontotemporal dementia	Employed	Yes	Social media
7	Edward	Judge	63	Male	Dementia	Retired	No	Social media
8	Anna	Nurse	62	Female	Alzheimer's disease	Retired	No	Social media
9	Rose	Team leader	58	Female	Alzheimer's disease	Employed	Yes	Social media
10	Chris	Mechanical Engineer	55	Male	Vascular dementia	Retired	Yes	Healthcare referral
11	Tom	Cinema Projectionist	63	Male	Corticobasal degeneration	Retired	Yes	Social media
12	Ken	Shop owner	62	Male	Alzheimer's disease	Employed	Yes	Healthcare referral
13	Joan	Head of Business Support	58	Female	Alzheimer's disease	Employed	Yes	Direct contact at event
14	Mary	Office Manager	55	Female	Alzheimer's disease	Unemployed	No	Healthcare referral
15	Alison	Maternity Care Assistant	52	Female	Alzheimer's disease	Sick leave (awaiting retirement)	No	Healthcare referral
16	Myra	Office Manager	53	Female	Alzheimer's disease	Sick leave (awaiting retirement)	No	Healthcare referral
17	Steve	Safety inspector	57	Male	Frontotemporal dementia	Retired	No	Healthcare referral

<sup>2</sup> Participants' names have been changed to protect anonymity.

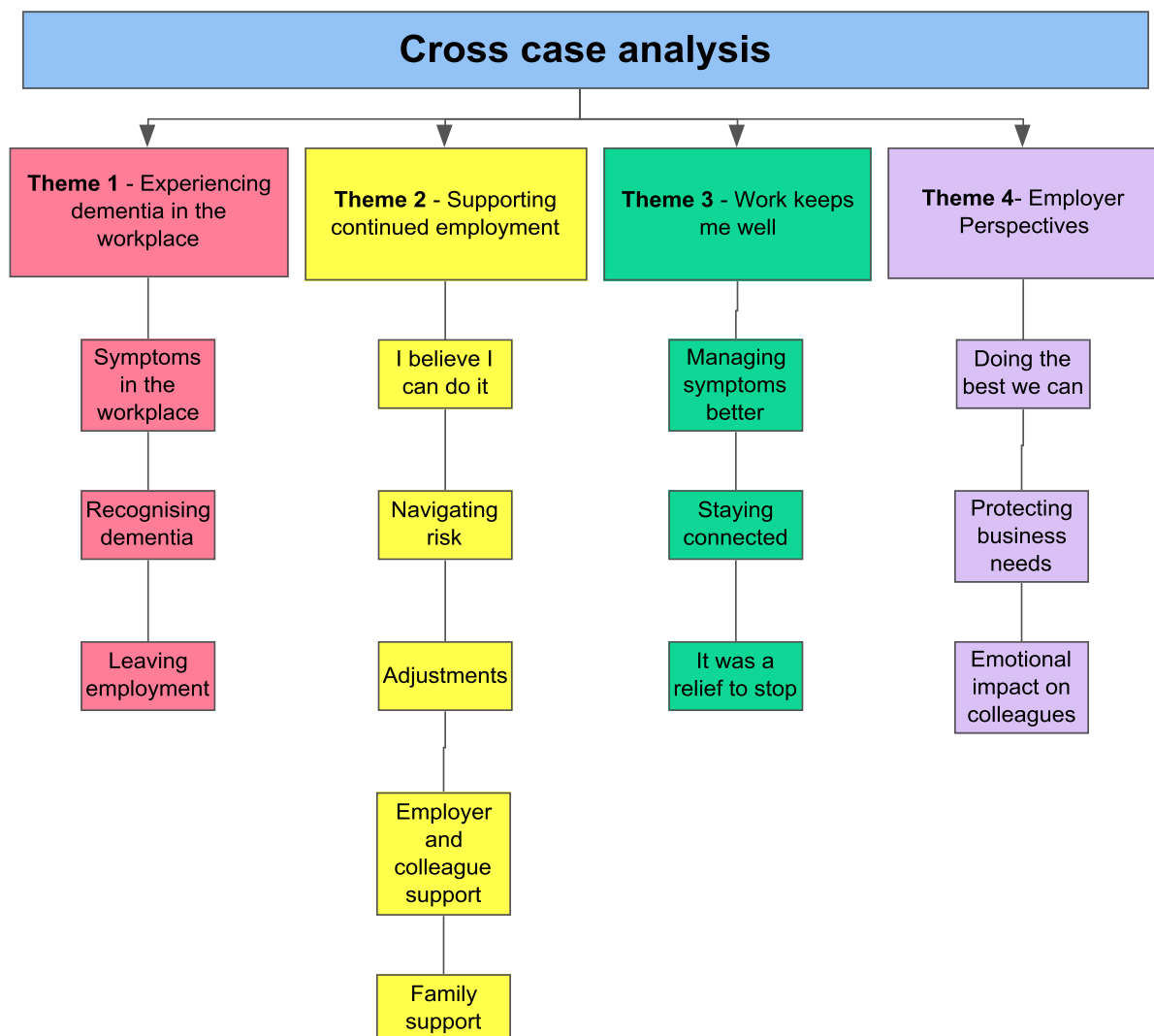
Table 4.2 Overview of the case study informants

No.	Name	Occupation	Family member	Workplace representative	Other participants	Documents
1	John	College Lecturer	Wife	Line manager		
2	Joe	Handy man	Wife	Line manager		
3	Michael	HGV driver	Wife			
4	Jim	Electrical Engineer	Wife	i)Human Resources manager ii)Occupational health nurse		
5	Paul	Council Officer	i)Wife ii) Daughter (via email	i)Line manager ii)Colleague/close friend		
6	Jack	Telephone Engineer	Wife	Line manager		Health passport
7	Edward	Judge	Wife			
8	Anna	Nurse	Husband	Colleague		
9	Rose	Team leader	i)Daughter ii) 2 <sup>nd</sup> Daughter (via email)	i)close colleague ii)colleague supervised by Rose iii)other team member		i)Email disclosing diagnosis to employer ii)Dementia awareness talk for staff
10	Chris	Mechanical Engineer	Wife			
11	Tom	Cinema Projectionist	Wife	Line manager		
12	Ken	Shop owner	Wife	Co-owner of shop/brother		
13	Joan	Head of Business Support	Husband	i)line manager ii)colleague line managed by Joan		
14	Mary	Office Manager			Psychologist who provides post diagnostic support to Mary	Job description
15	Alison	Maternity Care Assistant	Husband	Colleague/close friend	Post diagnostic support nurse	
16	Myra	Office Manager	Husband	Line manager		
17	Steve	Safety inspector	Partner			

### 4.3 Cross case analysis

A thematic cross case analysis was carried out based on the emerging themes from each case study (Braun and Clarke, 2006). Differences and similarities were examined between cases based on the employment status, gender and organisation type of the participants using a matrix approach (Yin, 2009). The cross case analysis produced four general themes in the data; Experiencing dementia in the workplace; Supporting continued employment; Work keeps me well; Employers perspectives. Each of these themes are broken down into subthemes which are outlined in Figure 4.2. The following chapter will discuss each theme and subtheme in turn to present a synthesis of the experiences uncovered in the case studies.

Figure 4.2 Outline of cross case analysis themes.



### 4.3.1 Theme 1 – Experiencing dementia in the workplace

Each case study presented a different experience of dementia in the workplace. However, from the case studies it was clear that employment was important to the participants and the cross case analysis highlighted similarities in the experiences regardless of the specific circumstances of each participant.

#### 4.3.1.1 Symptoms experienced in the workplace

Participants spoke of the problems they experienced in their workplace because of the symptoms of dementia. These problems differed depending on the type of job the person did and the skills that were required of them. However, there were similarities in the types of symptoms they had and the impact these had on their employment. There were also differences between case studies as to which point the symptoms began to affect the performance at work. For the majority of participants there was an impact on their employment before they had a diagnosis, however in two cases (5 and 13), they received a diagnosis before there was any perceivable impact on their work.

Memory problems were the most commonly reported symptom of dementia by participants in the case studies. These were initially small memory failures, such as forgetting a meeting or misplacing keys, however as time progressed they became more pronounced and had a bigger impact on the participants' performance in the workplace. Examples of these were forgetting to wear ear protectors in a loud environment and forgetting procedures of how to do a task that they carried out daily.

*I had to write things that I had known for years down. (Chris, Engineer, Case study 10)*

However, for some participants, memory problems were not the symptom which caused them most concern in the workplace. Participants also spoke of experiencing episodes of confusion and disorientation in the workplace, where familiar environments became unfamiliar. Rose, in case study 9, described an experience where she came out of her office as she did many times a day and did not recognise her surroundings.

*I came out of my office and didn't know where I, didn't know where my office was or who all these people were or who was behind the closed doors.... I simply walked down to the end of the corridor and, and out the other door to wait for this fog to clear (Rose, team leader, case study 9).*

Rose was left feeling vulnerable in her workplace following this experience and this affected her confidence in continuing work. Like other participants, she felt that, although she could cope in work at the present moment, she began to question how long she would be able to continue.

Other participants, rather than describing confusion or disorientation as a symptom, spoke of noticing non-specific changes in their cognition, such as feeling that they were not able to access and process information as quickly as they had before. John, in case study 1, felt this was the initial symptom he had experienced while working as a journalist. In his case, his skills lay in being able to have a quick response on live radio and process information quickly. Although he had no specific difficulties he felt that his response time slowed and he had trouble keeping up with the flow of the programme. He described this as:

*I started recognising that I wasn't quite as sparky as I once was and that's all you put it down to, just a, a dulling of the senses. (John, journalist, case study 1)*

Problems with communication in the workplace were also common for many of the participants, especially within meetings. For many participants meetings became really difficult as they could not follow the flow of the conversation. For Rose in case study 9, meetings became difficult unless she was chairing them as she had control over the subject and knew what was information she required from the meeting.

*If I'm in control of the meeting then it's no problem but if I'm taking part in a meeting and I'm not quite sure of what's going to be asked of me then I, I tend to get in a real muddle and I can't take it, take in what's going on. (Rose, team leader, case study 9)*

Similarly, Joan in case study 13 spoke of how she found it difficult to follow the train of conversation, often not realising when the topic of the conversation had changed, which can cause confusion for her colleagues as well, as she explained:

*We've got a lot of different grants coming in at the moment and they've got similar titles, and he'll be talking about one and then he'll switch to another and I don't cotton on that he's switched to another so I carry on giving him information relating to the first one (Joan, head of business support, case study 13)*

Problems with written communication were also common; for example, participants often felt that they had difficulties with composing emails or with writing reports where they had to transfer notes they had taken into a standard format. For Steve in case study 17, this was the main problem he was having in his employment working as an offshore safety inspector. Although he still had the skills to inspect the work being done and spot the faults, he quickly lost the ability to translate that information into the standardised report required.

*He ended up coming home after 2 weeks offshore with stacks of information and it hadn't been transferred onto reports, so then we were sitting trying to do it. (Steve's partner, case study 17, off-shore safety inspector)*

Participants whose work involved calculations, or working with money, often found that they first noticed difficulties with these aspects in their workplace. For example, Ken who ran a shop with his brother, the first difficulties arose when he was handling money; as his brother explained:

*That's one of the first things that went was understanding of money. He said I try at night, I lay it out and I try to identify it but it just all looks like Mickey Mouse you know. (Ken's brother, shopkeeper, case study 12)*

Changes in the participants' personality were also noticed as an initial symptom in the workplace. Participants themselves did not report any personality changes, however work representatives and family members reported noticing changes. These included changes in the participants' responses, for example they became more challenging or defensive when asked to explain a mistake. The occupational health nurse in case study 4 described how she had noticed a change in Jim's behaviour when she began to ask him about his memory problems. She spoke about

how they had previously had a very good, friendly relationship but she felt his behaviour had changed towards her and he was more aggressive.

*I could go so far as to say quite aggressive and Jim was never aggressive with me prior to that. I was speaking rubbish, everybody was speaking rubbish and that went on for quite some time and that was really, really difficult.* (Jim's occupational health nurse, Engineer, case study 4)

As would be expected, there were many similarities in the symptoms of dementia experienced by participants, however no two experienced them in the same way. On the point of whether the participant could continue employment, what was important was how the symptoms experienced affected the specific job the person was employed to do. If the symptoms of dementia directly affected their key skills needed for their job, then continued employment became more difficult. For example, John in case study 1 found it difficult to continue working because his main problems were with reaction time and communication, both of which are important to be able to do his job as a journalist and a lecturer.

*I was always contributing to radio programmes which very much relies on spontaneous response, improvisation, where you'd have a general theme and work round it and I started recognising that I wasn't quite as sparky as I once was and that's all you put it down to, just a, a dulling of the senses.* (John, case study 1, journalist/lecturer)

However, in situations where the participant continued employment, the main skills they used in their job were largely unimpaired and the problems they had were easily managed using coping strategies or small adjustments. For example, Jack in case study 6 was able to continue working in his role as a telephone engineer because his technical knowledge was unimpaired and small adjustments, such as providing screens to reduce background noise, were all that was needed for him to be able to continue working.

#### **4.3.1.2 Recognising dementia**

The length of time it took case study participants to get their diagnosis of dementia varied from a few weeks to a number of years. Getting a diagnosis quickly helped many participants to continue working, as this meant that they were aware of what was causing their problems and they were able to access and put in place the supports needed to help them stay working.

*One factor that did play a part was the fact that my mum pushed for a diagnosis early on.* (Paul's daughter, case study 5, council officer)

However, for many, there were obstacles which delayed their diagnosis of dementia resulting in them striving to cope in the workplace without understanding what was causing the problems for a longer period of time. One of the main barriers to getting a diagnosis that was identified in the case studies was how the symptoms of dementia were recognised in the participants, particularly when they were in their 50s.

In the majority of case studies, the participants, family members and, in most cases, workplace representatives were aware of the changes in the participants' cognition and could see that this was affecting their performance in the workplace. However, initially these changes were explained by other health-related or situational factors and dementia was not considered. An

example of this was in case study 3 where Michael was working as an HGV driver. He began to have problems carrying out his paper work and couldn't organise his workload. Initially, he put this down to the fact that he had recently started wearing glasses, as this meant he had one more thing to manage:

*So at that same time I was having to wear glasses to read stuff and which I was finding quite hard actually because when you're trying to organise something in a truck and you've got all the paperwork lying and your run sheets and that I'm sitting trying to get my glasses on, which I'm not used to doing. (Michael, Case study 3, HGV driver)*

Similarly, increased stress was often cited as a cause of changes in participants' performance at work, this may have been due to personal or family issues or related to changes in the workplace. In many cases, participants attended the GP about their problems and were signed off work due to work-related stress.

*I said okay, right, let's get through this period then the stress will hopefully go away and things will get better. So, that carried on for another couple of, well I carried on for another couple of years. (Joan, case study 13, head of business support)*

Other participants were diagnosed with other mental health problems, such as depression or anxiety when they first went to the doctors presenting the initial symptoms of dementia. These different diagnoses delayed the time it took for the participants to get a diagnosis of dementia.

As well as the symptoms of dementia being misdiagnosed, in three of the case studies the ladies involved were told by the GP that their memory problems were a result of the menopause. In all three cases, they struggled with completing their jobs and became increasingly susceptible to stress in the workplace. This ultimately led to them leaving work before they had a diagnosis, either on sick leave or being dismissed, as the situation began unmanageable.

*I didn't notice it, at the beginning I thought it was all because of the menopause; it was horrendous to be quite honest..... and then one day I was going in for a meeting and I hadn't been doing well, I'd made a couple of wee mistakes... they asked me to come for a review and they said that, that I would never work again and that was it. (Mary, office manager, case study 14)*

The time between being referred for further tests and getting a diagnosis of dementia varied greatly in the case studies. John in case study 1 highlighted how waiting for a long period of time to get a diagnosis left him feeling confused and worried about what was causing his problems.

*So I've been stumbling around trying to make sense of it whilst, you know, professionals were going 'oh it could be this, could be that.' I think there was a, an awful lot of reticence to give it a name. (John, Case study 5, lecturer/journalist)*

For many participants this left them feeling in limbo and unsure how to proceed in their workplace, resulting in many going on sick leave before they had their diagnosis. This meant when they finally received the diagnosis, they were relieved to know exactly what was wrong with them and to be able to move on with accessing support.

*It was relief that yes, there is something there and then there is something wrong, but then I've known with all the not remembering, I knew there was something. (Myra, Case study 16, office manager)*

The fact that dementia is not commonly associated with people of working age explains why, for many of the participants when they began to experience the symptoms of dementia, it was not straight away recognised as dementia. For the participants, their families and work colleagues the other reasons given for changes in behaviour led them to believe that these changes were temporary and made it easier to deal with the changes they had noticed. Receiving a diagnosis of dementia meant that these changes were not temporary which was difficult to deal with for many people.

*There is a dread term in the diagnosis which is degenerative and the minute you know, this, it's not getting any better than this pal. (John, case study 1, journalist/lecturer)*

While it is clear from the case studies that an early diagnosis of dementia is beneficial for helping to support a person to continue employment, they have also shown that getting a diagnosis of dementia while of working age can be complex and lengthy, for a number of reasons.

#### **4.3.1.3 Leaving employment**

In nine of the cases, the participant did not continue working post diagnosis, and in seven of these cases the person had left work or went on sick leave before they got their diagnosis. Further to this, of the eight people who continued employment post diagnosis, three of the participants had left work at the point of interview. The process of leaving employment was challenging for many of the participants, especially those who had had to leave work under difficult circumstances. As highlighted above, for many participants the situation in their workplace became untenable, resulting in them being dismissed or put on sick leave before they got their diagnosis. When they did receive the diagnosis, employers started the process of terminating their employment. For the majority of participants this meant applying for early retirement due to ill health.

Many of the organisations had a policy of offering redeployment or retirement for employees who could no longer carry on their job. However, in the cases where this was available, participants felt that it was offered as a token gesture and that employers were keen to push the retirement angle. An example of this was in case study 15, after it was decided Alison was no longer able to work as a maternity nursing assistant following her diagnosis.

*The first meeting we went to they said there was like 3 options which was retirement, retirement due to ill health and redeployment but the redeployment, it was just kinda mentioned and moved on. That was how I got the impression right from then that they were just going down the retirement thing, whether Alison wanted to or not. (Alison's husband, case study 15, Maternity care assistant)*

The exception to this was in case study 4, where although Jim had been assessed as not being competent to work as an electrical engineer, he was able to work in a non-safety critical role and was offered a part-time post working in the store room. However, this would be at a lower salary it would have implications for Jim's income and pension when he did retire. Because Jim refused to take the part-time post, his employers attempted to terminate his employment. This would have



happened if it was not for the intervention of Jim's union representative and his wife who had him signed off work sick for 18 months until he reached retirement age of 65. However, she felt that as soon as this has happened, they received no support from the workplace and this left Jim feeling disappointed with how his working life had come to an end.

*She'd offered him a part time on the line but we went to doctors and he started signing him off and Jim had paid into his work for a PHI, which is permanent health insurance, so I got a booklet about that and it had to be filled in by, I think it was the 6th of January. Nobody helped me from there. (Jim's wife, case study 4, Electrical Engineer)*

Many of the participants felt that the process of leaving employment could have been handled better by their employers. They felt that they had little control over the outcome of what would happen and that they were left a long time waiting while a decision was made on the outcome of their employment.

*But we've waited that long for the diagnosis, we're just waiting time now, we're getting used to waiting time ... So we don't know, 3 weeks to 3 months [before they make a decision] (Myra's husband, case study 16, office manager)*

Perhaps the most extreme example of this was Edward in case study 7, who was a Judge. Edward had continued to work up until he was diagnosed with dementia and informed his employers shortly after his diagnosis. He was immediately told to go home and they would contact him regarding what would happen. It took two years for his employers to reach the decision that he would be given early retirement due to ill health. Throughout this period, Edward had very little contact with his employers, and he was not kept informed of the processes that were going on. He was referred to ATOS for occupational health assessments and these occurred over the phone.

*Anyway this ATOS doctor was perfectly nice phoned me up and said he was an occupational health doctor and I said "fine" and he gave me some; you know said that they would get evidence from my doctor and get a second opinion if necessary and I said that was fine. Then he rang me back after quite a long time and said "I think you shouldn't", he said "I'm not going to take another view because of all the medical evidence from your GP, I'm happy that you shouldn't be practising as a judge". (Edward, case study 7, Judge)*

Edward felt he had no control over his employment situation and no choice in what the ultimate decision would be. This had a negative effect on Edward's mental health and he was diagnosed with depression throughout this period. He was eventually told that he was being retired due to ill health.

*I was sat at home and no decisions made until much later on when they suddenly said "we're going to retire you". (Edward, case study 7, Judge)*

This had an impact on his pension as well as his ability to work sessionally as a Judge as many do during retirement. Although Edward had a good salary as a Judge, these changes to his pension meant that he and his wife had to make a lot of adjustments to their lifestyle and their plans for retirement as a result of the reduction in income.

*There's a loss of earnings to it, and potentially a large loss. (Edward, case study 7, Judge)*

Loss of control was a common feeling amongst the participants who had to leave work. Alison in case study 15 had to go on sick leave from her job as a maternity care assistant before she got her diagnosis. When she informed her employers about her diagnosis she was left waiting for a number of months while her employers assessed her and decided what would happen with her employment. Alison felt that not knowing what was happening and not feeling in control of the situation was having a negative effect on her mental health. However, Alison, with the support of her family and support nurse, decided to regain control of the situation and made the decision to take early retirement. This helped her to feel in control of her future and helped her deal with the end of her working life better.

*Cause you appeared to feel so much better once you'd made a decision...But while, while, during the period that it was still with the NHS, the NHS appeared to have control, your, your anxiety was getting worse and worse worrying about the future, that's how it seemed.*  
(Alison's support nurse, case study 15, maternity care assistant)

Participants who had to leave work when they were diagnosed with dementia tended to have more financial problems. This included a reduction in pension, problems paying bills such as mortgages etc., not being eligible for sessional employment post retirement, and problems accessing benefits. Mary in case study 14 was dismissed from work when she began to experience symptoms of dementia without any redundancy pay or support from her employer. This left her without income and reliant on her family for support as she wasn't eligible for unemployment benefit.

*I've not had any money since September last year.....I owe my mum quite a lot of money, I owe my brother.* (Mary, case study 14, office manager)

However, as Anna in case study 8 highlighted, for many participants although they made the decision to leave work, it was still a very difficult decision to make and found leaving work very emotional.

*So that was sad, I was very sad to leave.* (Anna, case study 8, nurse)

For all the participants who had left employment, the experiences varied greatly, however it is clear that they all felt that there could have been more support and understanding to assist them in the process of leaving employment and dealing with the associated paperwork for pensions and benefits.

### **4.3.2 Theme 2 – Supporting continued employment**

#### **4.3.2.1 I believe I can do it**

The participants' feelings towards working post diagnosis were important for whether they could successfully continue employment. For many participants receiving a diagnosis of dementia had an impact on their self-belief which made them question whether they were able to continue working and how much they were able to contribute if they did. Many of the participants who did not continue working felt that they would like to continue but were unsure of what they would be able to do, especially when going back to their previous job was not an option. Many were worried about having to learn new skills or not being able to remember what they had to do and so did not feel confident enough to go back to work.

*I mean I couldn't do my job. I could not physically do that job and if I think about it because in any of, any job you've still got to remember what you've to do. Well there could be some days where I can't remember. (Myra, case study 16, office manager)*

However, for the participants who continued working, there were a number of factors which seemed to help build their confidence in their ability to continue working. This included their access to medications and being able to continue working throughout the period they were diagnosed.

All of the participants who continued employment had some form of medication or treatment which they believed was helping control their symptoms. For some this was Alzheimer's medication and others it was medication for depression or anxiety and others were using non-pharmacological treatments such as vitamin B and brain training. The participants who did continue working believed that the medication had improved their symptoms and was contributing to them being able to continue working.

*I saw the Oxford paper on Vitamin B, so, I thought oh, what the hell I've got nothing to lose so I started taking the high doses of it. Miracle. Absolute miracle for me. I, I still can't believe it. My brain now is, I feel like it was 4 or 5 years ago. I'm really much, much better. A lot of the symptoms are still there but not as badly as they were. (Joan, case study 13, head of business support)*

Although many of the participants who did not continue working were also on various medications and treatments, there was little evidence that they perceived these as having a big impact on their cognitive functioning which would help them to go back to work.

The use of medication doesn't seem to be the only factor in developing a belief they could continue working. The continuity of employment throughout the diagnosis period was important for people to develop a belief that they could still work with their diagnosis of dementia. The majority of the participants who continued employment did not have any extended periods of sick leave before they received their diagnosis indicating that they were able to manage their employment up until they got their diagnosis. As Rose explained, she knew that she was still able to do her job and was confident in her abilities.

*That's why I'm comfortable at the moment carrying on working because I still know more than [her team]. (Rose, case study 9, team leader)*

The two exceptions to this were in case studies 2 and 11 where both participants returned to different jobs following a number of years of not working after they got their diagnosis. However, in both of these cases, the participants had physical symptoms and once they had managed these felt more physically able to return to work.

*I kept on saying once I got the operation on the hand, that's, oh that'll be me. I'll be better, be back in there you know. (Joe, case study 2, handy man)*

#### **4.3.2.2 Navigating risk**

There are risks associated with the continued employment of a person with dementia. In some case studies, these risks were obvious because of the type of job the participant did. Jobs such as HGV driver, nurse and engineer involve elements of being responsible for public safety, while being a

Judge involves aspects of public responsibility. In other jobs, however, there are elements of risk to be considered in terms of the safety of the participant and protecting the needs of the business. Risk was an important aspect in most of the case studies, and in order to support the continued employment of people with dementia it needs to be navigated carefully.

In the period before they received a diagnosis, many of the participants experienced problems in their workplaces where they were making mistakes or not completing work. In many of these situations, colleagues and/or family were aware of these changes; however, they were unlikely to address the problem. What seemed to be important was that the other case study informants based their assessment of the situation on the participants' previous abilities. This meant that the risk being presented in the workplace was not always addressed in the most appropriate way. It was common that workmates and line managers would attempt to cover up problems or take on extra work for the participant in order to protect them from any repercussions from senior management. This was clear in case study 17 when Phil's partner explained that his colleagues had been fixing the reports he was submitting which were not up to standard.

*I phoned his, his immediate senior, who said yeah they had, they knew something was wrong but because he's self-employed and he's got such a knowledge of his craft they were kinda just come on in and we'll fix it and it was just like seen as an idiosyncrasy (Phil's partner, case study 17)*

This highlights that workmates were basing Phil's performance in work on what they felt he was capable of rather than what he was able to do at that point in time. Despite Phil's diagnosis, he still receives offers of work on the back of his reputation while he was working.

*He still gets offered work which is just wild. (Phil's partner, case study 17)*

It was common in the case studies that when the early symptoms of dementia emerge they are often noticed in the workplace but not assessed as something which may cause risk. Instead they are overlooked as something which is out of character and workmates tend to cover up mistakes to protect their colleague. Although no serious incidents were reported in the case studies, there was potential for harm to be caused to the person or another person and some mistakes could be classed as 'near misses'. This highlights the need for early action in the workplace when someone is perceived as struggling with their job.

The insight people have into their symptoms and their impact on their work also seems to be important for managing risk in the workplace. In a number of the case studies, the participants demonstrated little insight into their symptoms. They felt that they were still able to do their job and that any problems were related to external factors. For example, although Phil in case study 17 retired from work when he received his diagnosis, he still believes his ability to do his job is unimpaired.

*I can do my job fine. (Phil, case study 17)*

Similarly, Jim in case study 4 was not aware that his symptoms were having an impact on his ability to work. This caused problems for his workplace in the months after his problems were identified and before he received his diagnosis. As his occupational health nurse explained, they were trying to support him to continue working whilst trying to remove the risk of having him working on anything

electrical. This caused problems as Jim's job was electrical engineer and he couldn't understand why he wasn't allowed to do the job he was good at.

*We were trying to keep him off anything electrical and he's saying why am I just getting this job, why am I going to do that. (Jim's occupational health nurse, Case study 4)*

In other case studies, participants demonstrated a good awareness of their symptoms and the result of this was them leaving employment before they were diagnosed as they realised they were not safe to continue working. An example of this was Anna in case study 8. Anna had worked as a children's nurse for over 30 years when she began to experience symptoms of dementia. She particularly struggled with numbers and calculations and this impacted on her ability to administer medication and fluids to patients. One particular incident highlighted this problem to Anna when she realised she could not work out how much more fluid to give a patient to complete his feed. She asked another member of staff to complete it and she walked into the office and resigned.

*I was still nurse enough to know that I was in a position where I could harm somebody... but I knew something was wrong, definitely wrong. (Anna, Case study 8)*

At this point, Anna's line manager was not aware of her difficulties and tried to persuade her to stay, again basing this on her previous reputation and abilities. Another example in a similar setting was in case study 15. Alison worked as a maternity assistant when her symptoms of Alzheimer's disease began to emerge. When she began to make mistakes and take longer to complete tasks, Alison was aware that something was not right and went to the doctors. At the same time her colleagues and managers had noticed that she was struggling as well and the senior midwives were instructed to observe Alison in the workplace and report back on her performance. Alison didn't speak about this in her interview, but her work colleague spoke about it and how she felt that Alison knew she was being observed and this in turn was making her symptoms worse as she felt under more stress.

*I think because of that she was getting even more nervous and more forgetful because she was well aware that they were monitoring what she was doing. (Alison's colleague, Case study 15)*

She also highlighted that it was clear to her and the other maternity assistants they worked with that Alison's behaviour was not because she wasn't pulling her weight, but that it was clear to them that there was something wrong, however they didn't feel they were in the position to raise this with higher grade staff.

*She was behaving as though she had something wrong with her instead of not pulling her weight. (Alison's colleague, case study 15)*

Ultimately, it was Alison's own insight and the support of her close colleagues that led her to make the decision to go off work. As Alison explained, she knew there was something wrong and she knew that there could be serious consequences to any mistake she made because of the type of job she had, so going off work sick was the best thing she felt she could do in that situation.

*I knew that I wasn't right but because it's dangerous for me to be there because you can't function on lesser than 100%, it's no good for anybody, you need to be able to help them. (Alison, case study 15)*

These examples highlight the potential risks associated with developing dementia whilst still in employment. It is important that these are identified as soon as possible, and acted on to manage the risk. It may be that in certain job types the only way to reduce the associated risks is for the person to stop working, or to be redeployed to another role. However it is important for employers to understand that the person with dementia may not be aware that their performance at work has deteriorated, without management having this understanding there would be problems putting adjustments in place to reduce the potential risks and to support the person with dementia to continue working.

It is clear from the case studies that, when it comes to negotiating risk relating to the continued employment of people with dementia, people have not received sufficient support. Although there were no serious incidents reported in the case studies, this was due to luck and colleagues' awareness rather than risk management.

#### 4.3.2.3 Adjustments

For the people who continued working post diagnosis, there were adjustments made to their roles, work environments and working hours. For some, these changes were minimal and for others they were more substantial. The exact adjustments made to each person's role varied depending on the job they were employed to do, however there were similarities in the types of adjustments made.

Adjustments to the participants' working patterns were common. For those who worked in office based jobs, they found that being able to work from home regularly was useful as it allowed them to work at their own pace and also cut down on distractions in the office which may cause frequent breaks in their concentration. However, for the participants who worked at home, they often used this as a way to keep on top of their workload by working additional hours, as Joan explained:

*I only do 3 days in the office and then I do, well, in theory, one day at home but I do at least 2 days at home but I'm only paid for the one day at home. (Joan, case study 13, head of business support)*

Flexible working was also a useful adjustment for many participants. This allowed participants to start work early or later allowing them to make the most of the part of the day when they felt at their best. For Chris in case study 10, this meant coming off a shift pattern completely and working a standard shift from 11-7. This cut down on the fatigue he was experiencing as a result of the changing shifts.

*I was getting so tired I liked a longer lie in my bed. I says to my line manager do you mind if I change my shifts, he says no, what do you want to do and I started doing 12 till, was it 12 till 8:36, and then he said, forget about the 36 minutes, he says just come in and do an 8 hour shift. I says right fair enough, so at the very end I was doing an 11 to 7. (Chris, case study 10, engineer)*

As Chris worked for a large private organisation which operated on a 24 hour a day basis, they were in a position to be able to offer Chris this flexibility. This was not possible in all cases where the business hours were more restricted. In these cases, reducing hours was a positive way of supporting their employees. For Tom in case study 11, he worked on a sessional basis as a

projectionist in a cinema and this allowed him to work as much or as little as he was comfortable with.

*It should've only been about 15 hours a week but some weeks I was working 20, 25 hours.*  
(Tom, case study 11, projectionist)

Changes to the persons' job description were another common adjustment in the case studies. These adjustments focused on what skills the person retained and adjusted their job to fit with their abilities, rather than focusing on aspects the person could not do. These changes included removing safety-critical aspects of the job and removing responsibility for line management of staff.

*Once we realised [what his diagnosis was] then we gradually took his responsibilities off him.*  
(Ken's brother, case study 12, shopkeeper)

For most participants, a change in their job description was reflected in a change in their salary. Depending on the job type, this was either a straightforward percentage reduction in salary or was as a result of a reduction in hours which reflected the reduced duties.

*Joan knows her role had to change, her salary's changed in relation to that role and she accepts that she's doing less of the job therefore she should be paid less.* (Joan's line manager, case study 13, head of business support)

Many of the participants had adjustments made to their work environment, as mentioned above; for example, being allowed to work from home cut down on the distractions of working in a busy office. When home working was not possible though, providing a quiet space for the participants to work was a common adjustment. This could be in a quiet office, or using dividers to reduce background noise.

*I found a nice little quiet corner away from everybody else.* (Jack, case study 6, telephone engineer)

The use of memory cues and coping strategies were frequently used by participants as well. Some found that the nature of the job they did provided the memory cues for the work that required to be done. For instance, Joe in case study 2, worked as a handy man in a care home and used the faults report book as his memory cue for what needed done each day.

*What we do with the maintenance team is there's a log book that gets filled in by the staff if there's anything needs done so it's a written piece of work for Joe to check every morning when he comes in and then sign off when he's finished it and so if he's, if he's not finished it he'll know the next day if he's started something.* (Joe's line manager, case study 2, handy man)

Other participants had to develop their personal systems a bit more and these relied on the support of their colleagues to work well. These included having all information written down, either in email or using post-it notes as reminders. Participants found that these strategies worked best when they had explained to their colleagues the challenges they faced and why each strategy helped them.

*I'm always saying you know I don't have a memory so don't expect me to remember anything and how they can help me is by, if they've got a question that I need to answer but*

*I can't answer immediately then email it to me or put a post-it on my, my desk, and when you're telling me something new you just need to be patient and let, let my brain catch up with what you're saying cause processing new information is, is difficult and ... they've all been great, I've had post-its galore, emails galore. (Rose, case study 9, team leader)*

Technology was also used by participants to assist them to continue working. These were small things such as becoming more reliant on a spell checker, or using instant messaging and email to keep in touch with colleagues. Mobile phones were often used as well for their calendar or alarm functions or, in the case of Joe in case study 2, using google to remind him how to fix a toilet seat when he couldn't remember how to do it.

*A lot of things I couldn't remember how to do, changing the lights, taking a light down, put a new one up. I could've done that in my sleep. Forgot how to do that. Fit a toilet pan in, forgot how to do that as well and I googled it, so I did. (Joe, case study 2, handy man)*

Overall, the adjustments made to the participants' jobs ranged from large scale changes which relied on policy and procedures to small adjustments that the participants themselves identified as being useful for helping them with specific tasks or difficulties.

#### **4.3.2.4Employer and colleague support**

The type of organisation the participants worked for was important for successful continued employment. This included the organisational culture, line management practices, and relationships with colleagues.

As many of the case study participants worked for large organisations, they had access to internal occupational health services. When the employee disclosed their diagnosis of dementia to their employers, many employers turned to occupational health for support. Overall though, occupational health advisors were not well informed about dementia, because they had not experienced it in the workplace previously. Rose in case study 6 spoke of how she had hoped that occupational health would be able to provide the support that her line manager had not been able to offer, however she was disappointed that they had no knowledge of dementia either.

*When I got there she was printing symptoms off the internet off the Alzheimer's website so I started off by saying oh, so have you not had, you've never worked with people with dementia or you've had any experience and she was, she was quite open and said no, no, I'm just printing off these questions to ask you, so that was a paper exercise really. (Rose, Team leader, Case study 9)*

This left employers in the situation where the employee was having to guide them on what was best for them, rather than the employer being able to make informed decisions on how best to support the employee within the company as a whole. For some of the participants, after the initial disappointment of not getting the support they expected, they worked with occupational health to explain the support they needed and they developed a support plan together. An example of this was in case study 6 where Jack and his wife worked with occupational health to write a 'health passport', which is an existing company policy to support employees with a disability. This gives Jack more security in his work and reduces his stress.



*So between us, him and I, we wrote what Jack needed, what needs to happen and did all of that and Jack now has a health passport, so which means that they can't throw new stuff at him and expect him to do it. There has to be more training. If he says it's too hard, I can't, I can't do that, so if they want to change his job they have to do a bit more work. (Jack's wife, telephone engineer, case study 6)*

As shown in Jack's situation above, employers often used pre-existing policies to support employees who developed dementia. In Jack's case this was a positive outcome which allowed him to continue working post diagnosis and at the time of his interview had been working for four years. The organisation that Jack worked for had a positive attitude to supporting employees with disabilities so their approach was easily adapted to support Jack. There were other similar cases to Jack's where the existing policies were adapted to support the employee. In other cases however, the main policy which was used when a person was diagnosed with dementia was related to capability and often resulted in the person being given the option of early retirement or redeployment. An example of this was in case study 15 where Alison worked as a maternity care assistant but began to struggle with her day to day duties. She eventually went on sick leave before she got her diagnosis but kept in regular contact with the Human Resources department while she was off. When she received her diagnosis it was assumed that she was not able to go back to her job because her dementia meant that she was not able to do the job. This meant that she was eligible for redeployment or early retirement from her post. However, despite giving Alison an occupational therapy assessment Alison, her husband and her support nurse felt that the option of redeployment was not taken seriously.

*They said there was like 3 options which was retirement, retirement due to ill health and redeployment but the redeployment; it was just mentioned and moved on. That was how I got the impression right from then that they were just going down the retirement thing, whether Alison wanted to or not. (Alison's husband, Case study 15, maternity care assistant)*

The direct relationships that the participants had in the workplace were also important. These included those with their line managers and those with colleagues. In general, the majority of participants perceived their line manager to be supportive. Having a good relationship with their line manager made it easy for participants to disclose their diagnosis and subsequently negotiate changes to their job.

*I told him the day after and he's just been great since, well before then, at that time and ever since. He, he couldn't have been kinder and he's not patronising or anything like that. (Joan, case study 13, head of business support)*

A good line management relationship for the participants included understanding, openness and a feeling that they valued them as an employee. Chris in case study 10 spoke about his relationship with his line manager;

*He bent over backwards and he was giving us flexible hours, he was putting us through for days off when I maybe didn't turn up. I said put me in for a holiday. Just forget your holiday, you know, he was, he really was good that way because of the fact his wife suffers from a type of cancer but thank god now she's really on the mend, so I think he could see it from another side if you know what I mean. (Chris, case study 10, engineer)*

However, many of the participants and their families felt that the line management relationship could have been improved. For some, like Paul in case study 5, this was related to the fact they felt the manager could have handled problems Paul faced in the workplace better.

*His boss was very good with Paul but he wasn't so good from the general work side from the point of view of keeping an eye on what was going on. (Paul's wife, case study 5, council officer)*

For other participants, communication problems with their line manager was a source of many of their issues in the workplace and, like the situation of Myra in case study 16, a breakdown in this relationship was one of the main reasons she felt could not continue working. This was due to the line manager being new to the job and not knowing that Myra was not functioning in work the way she used to. Myra was unable to explain why she was making mistakes and blamed this on the new line manager's unreasonable demands. However, her line manager had a different view of this and also found the situation distressing.

*I tried to do as much as I could to, to support Myra and to try and help her and I know Myra had said several times that it was me, that there was nothing wrong with her and it was my unrealistic expectations of her that I'd come in and was very demanding. (Myra's line manager, case study 16, office manager)*

Similarly, the colleagues of participants had a role to play in supporting continued employment. Co-workers were important for giving emotional support and friendship to the participants as well as stepping in and taking on additional work or roles which the participant could no longer do. In the situations where participants worked as part of a close team of employees, this support was seen as 'what they do' being part of a team.

*As individuals we all have strengths and weaknesses and you try and address that at all times and also you get supported in the work room within, you know, all staff members but also especially within your curriculum area where you know if that aspect of delivery is not your strongest point, one of the other guys would step in and do it you know. (John's line manager, case study 1, journalist/lecturer)*

In other situations, there were more formal arrangements made with colleagues to provide support to the participant, such as their job descriptions being altered to officially take on additional duties. In these situations, colleagues viewed this as a training and development opportunity for them, as well as being able to support their colleague.

*I have taken on more but for me, I wanted to do that anyway. (Joan's colleague, case study 13, head of business support)*

The attitudes of colleagues were not always positive towards supporting their co-worker. In two of the case studies, colleagues were not supportive and, in case study 6 especially, there was evidence of workplace bullying from some. Although this did not stop Paul from continuing working, it did make things more complicated to manage for his family.

*This was one thing that became an ongoing difficulty for the remainder of the time that dad was working - i.e. trying to understand when there was a real issue v's some colleagues'*

*troublemaking v's my dad's interpretation of the situation. (Paul's daughter's email, case study 5, council officer )*

Because there were many differences in the organisations the case study participant worked for, it is difficult to say exactly what aspect of the employer and colleague support was important for supporting continued employment. Participants who continued in employment worked in various sizes of organisations and these had different capacities for facilitating this. In larger organisations, the employers had the resources, policies and flexibility to support their employees with dementia, while the medium and smaller size organisations had close relationships and loyalty which allowed them to support employees with dementia.

#### **4.3.2.5 Family support**

Families were an important source of support in all of the case studies. Family members were important in the process of getting a diagnosis, often being the people who instigated the first trip to the GP regarding changes they had noticed.

*I took him about 4 years ago with the first concerns with a list. (Steve's partner, case study 17)*

They were also important in keeping an open dialogue with the employers, regardless of whether the participant continued or left employment after diagnosis. As described above, Paul's family were an important support for his employers when he continued working post diagnosis. However, in other situations, such as case study 4, Jim's wife defended him in his work and her intervention stopped him being dismissed from his work and protected his pension.

*So he got these minutes [from a meeting with HR] and it said you will be gone by the Friday. This was Tuesday and by good luck we had the doctor on the Wednesday and I took the minutes in and he started signing him off. (Jim's wife, case study 4, electrical engineer)*

In other cases, it was the spouse who disclosed the participants' diagnosis of dementia to the employers and negotiated the terms for them leaving work. An example of this was in case study 17 where Steve's partner spoke to his line manager and discussed how best to manage the situation as he was not able to return to work for health and safety reasons. They worked together to achieve the best outcome for Steve which was for him to put in a notice of retirement and explain that this was because of a cut in pay.

*I phoned his, his immediate senior, Andy, who said yeah they had, they knew something was wrong and he said so they just basically said put your retiral letter in, retire, don't say anything about being ill. (Steve's partner, case study 17, off shore safety inspector)*

Mary in case study 14 had very little family support in her workplace for a variety of personal reasons. This left Mary in a vulnerable situation where once she began to experience difficulty in the workplace she was dismissed from her job. This left her in a difficult position with no income and no entitlement for benefits for a long period of time until she got the appropriate support post diagnosis.

*We're split, right but he stays in the house and he's hardly there but because he's in the house I don't get any money and I've not had any money since September last year. (Mary, case study 14, office manager)*

Many of the family members included in the case studies were still employed themselves. In the cases where the participant was no longer employed, many of the spouses continued working because they felt they had to, and that there was increased financial pressure on them to continue working as a result of the loss of income from their partner stopping work.

*I mean I've always been the main earner since [son] was born, but I wasn't expecting to be the only earner and that's really put pressure on us as well financially. (John's wife, case study 1, journalist/lecture)*

In the case studies where the person continued employment post diagnosis, many of the spouses felt that this allowed them the time to also continue working, which would give them financial stability for longer. Given the uncertainty of the progression of dementia there was a feeling that employment gave them a sense of normality, however they worried about how long this would last.

*I'm holding financially everything together, so I don't know. If I'm honest I'm frightened, I'm frightened about what the future's going to hold. I'm frightened for Jack. (Jack's wife, case study 6, telephone engineer)*

Supporting their partner with dementia had an impact on the employment of family members as well. For many, keeping in contact with their spouse throughout the day, whether they were employed or not was a challenge. For some the resources they had in work made this fairly simple, however, for others, this meant changing their working pattern or job in order to be in a position to work from home on a more regular basis.

*He was phoning me at work, at some points he was phoning me at work crying you know. He just, I can't do it, I can't do it and he was just panicking and, and wanted a reason or an, or you know, need to phone his work to get him home. Meanwhile I was still at work you know so yeah. (Michael's wife, case study 3, HGV driver)*

Balancing caring duties with employment was also difficult for family members and they spoke of increasing stress and burden. This was eased with understanding employers, however not all family members were in this position. Steve's partner in case study 17 had a particularly difficult situation in her workplace and she was becoming increasingly stressed at work as she was not allowed flexible working to support her partner to appointments.

*I have very poor support. They don't understand the carer's legislation... I've been taking half days for 11 years I have been told that I can now only take whole days when I said could I not please keep taking the half days because I don't know what's coming. They said with the, with the diagnosis as it was they didn't expect that I would have many appointments because there was nothing they could do. (Steve's partner, case study 17)*

Overall, family support was integral to supporting the participants' employment, whether they continued employment or not. For many family members they took on the role of advocate in the workplace to ensure their family member was being treated appropriately and getting the support

they needed. While there were many challenges associated with this, for the majority they realised the importance of their role and the fact that if it was not for their interventions the outcome of the employment situation for their family member may have been very difficult.

### 4.3.3 Theme 3 – Work keeps me well

Many of the participants who continued employment felt that working played a part in helping them to live well with dementia. This theme identifies the impact that continuing employment had on participants and, in contrast, the impact leaving employment had on participants. This will be presented in the subthemes: managing symptoms better; staying connected; it was a relief to stop.

#### 4.3.3.1 Managing symptoms better

Continued employment was highlighted as having a positive effect on how a person with dementia managed their symptoms. Participants spoke of work helping to keep their brain working and providing challenges for themselves which they had to work out strategies to overcome. There were two main reasons that participants felt continued employment helped them to manage their symptoms. Some participants attributed it to the challenge of working which helped them to keep their brain active. For example, Joan in case study 13, spoke of how working as Head of Business Support was important to her for the potential benefits it had for her brain functioning, rather than for the financial benefits.

*The more I do, the longer I'll keep some sort of good function there. (Joan, Case study 13, head of business support)*

Similarly, Joan's husband agreed with this view, highlighting the skills she was retaining:

*She feels a lot better, a lot more confident. Her memory, her long term memory's pretty good. (Joan's husband, Case study 13, head of business support)*

In case study 2, Joe felt that going back to work helped him to develop his confidence as he was put in the position that he had to communicate with other people and his work was providing a challenge for him he hadn't been getting from being at home. Joe's wife spoke of how she felt that going back to work was the best thing he could have done.

*I definitely have noticed a difference since he's went back to work. He's not nearly as bad. The jumbling up of the words isn't as bad..... He's a lot cheerier and he's a lot more talkative. (Joe's wife, Case study 2, handy man)*

Another reason participants felt working was beneficial for them was the routine associated with working, either in the routine of getting up and going to work each day or within the workplace following a set routine to carry out work tasks. For Jack in case study 6, the routine of getting up every morning and travelling to work with his wife is followed by a set routine in his work which helps him feel secure as he knows he is able to manage his day as he explained:

*First thing in the morning you'll get the overnight work ..... so you do that but you just will take them one at a time, just work through it nice and steady and you just change the title to put, and put your name in it and close it down again so somebody else can see that it's been dealt with. So we have that routine to work through, which is nice. You know, it works. (Jack, Case study 6, telephone engineer)*

Working as part of a team with a set routine helps to manage the stress of the job, Jack is aware of what is required of him and doesn't feel under pressure at any point to complete all the tasks. Jack's line manager was also aware that the routine of the job was beneficial for Jack.

*I think he is of the opinion that it's doing him good. I think what he obviously needs is routine and it's a routine he can cope with. (Jack's Line manager, Case study 6, telephone engineer)*

This means that Jack is able to continue working within his capabilities without putting additional pressure on himself. Jack's wife highlighted how she feels that him continuing working has helped him to control his symptoms of dementia.

*Jack is so well and actually statistically shouldn't be so well. (Jack's wife, Case study 6, telephone engineer)*

Similarly, routine was important for Ken in case study 12 who continued to work in the shop he ran with his brother after his diagnosis of Alzheimer's disease. Ken's brother explained that he felt by keeping Ken at work he was retaining skills and functioning that would otherwise be lost. He explained this by highlighting how Ken has lost skills he used in the shop when his routine was disrupted, for example when he was in respite for a week and not in the shop.

*We found that if he stops doing something then he totally forgets how to do it. If you can keep him doing it he would, he can do it. (Ken's brother, Case study 12, shopkeeper)*

Overall, the participants who continued working felt that by doing so it was helping them cope with their diagnosis and manage their symptoms. It is not clear from this information what is influencing the participants' perception that work keeps them well, there may be many other factors involved which keeps them well enough to work, rather than work keeping them well. What this theme does show, though, is that the participants placed a value on being able to continue working.

#### **4.3.3.2 Staying connected**

Continuing employment post diagnosis of dementia was also seen as a way of staying connected with their wider community. Given that the participants were all diagnosed with dementia when they were still of working age, those who left work following their diagnosis were left in the position that they did not have activities or social networks who were not at work. In many areas there is a lack of services for younger people with dementia which means that they struggle to feel like they belong there. Tom in case study 11 found this after he left work following his diagnosis. He was placed in a day centre for older people and was left feeling under-stimulated and undervalued.

*I just said well I'm not doing any more of this, I, I, I'm bored and I'm, I'm not stimulating myself. I'm not, I feel as if I'm worth more than this. (Tom, case study 11, projectionist)*

Tom subsequently returned to work as a projectionist after this experience as it helped him to realise he was still able to contribute to his community. However, for other participants their experience of leaving work before their planned retirement age has resulted in them spending a lot of time alone in the house with little social contacts. Because so much of their social networks were linked to their workplace, leaving work has resulted in them losing contact with a lot of friends.

*You feel quite remote you know because you've been taken out the work environment you know, meeting your mates every day and having a laugh and you know maybe have them for a beer at the weekends or something, I've lost track of my, they've moved away and I've lost track of my mates when I got diagnosed. (Michael, case study 3, HGV driver)*

Although some of the participants felt their friends still tried to make an effort to see them, many of them, especially the male participants, felt they couldn't be equal partners in the relationship as they used to be and that their friends who did make the effort were doing so out of a feeling of duty.

*I appreciated them all coming out to the suburbs here and seeing what was what, but I, you know, you can't connect with people the same. You can't just come out with the same old anecdotes or updates of them. (John, case study 1, journalist/lecturer)*

For female participants who left work, maintaining friendships was easier for them as their social networks were wider and not focused solely on their employment. They also had more friends who had retired early or worked part-time hours.

*I've got girls ... we were all working together years ago and we all go out on a Tuesday. (Myra, case study 16, office manager)*

This issue around feeling socially isolated, particularly in the male participants, may link more widely to a feeling of loss of identity from leaving employment. For many participants, their identity was closely linked to their workplace. What they did for a living and providing for their families was integral to how the participants viewed themselves. When they were unable to continue working, much of this was lost and they suffered a loss of confidence and they could no longer fulfil their sense of identity.

*It's just coming to terms with it but the diagnosis was the, the biggest thing and you kinda feel like you're not in control ... I was in control because I was the, the wage earner, paid bills, you know fixing the problems, dealing with things and then a month down the line that's just all taken away from you, so you're like feeling quite useless and worthless. (Michael, case study 3, HGV driver)*

Some participants engaged in voluntary work or other activities throughout their working lives which they were able to continue working on after they left work. Whilst stopping work was very upsetting, having pre-existing interests and activities seemed to help protect their sense of identity and confidence. Anna in Case study 8 continued to engage with a number of activities post retirement, such as volunteering with a local charity, getting involved with local dementia support groups, giving dementia awareness talks and continuing with her existing interests. Anna felt that these activities provided meaning to her life and allowed her to continue functioning well as she explains.

*I think it's really important to keep active because I'm sure, you know I've had my diagnosis for a few years now and I expected me to be worse than this and everyone else expected me to be worse than this, so I can only assume that it's because I have kept active and involved. (Anna, Case study 8, nurse)*

For the participants who did continue working, although adapting to their diagnosis was difficult, being able to stay in employment meant that they did not experience the same feelings of loss as they managed to keep a feeling of normality and connectedness by continuing employment.

*What kept me going was see the guys that I worked with, an absolutely fantastic group of guys, couldn't ask for better honestly and I think that's what really kept me going because even when I was off, the banter, I totally missed the banter. It was absolutely fantastic, know they kept you going all the time and you got a bit of a laugh and a joke you know.*  
(Chris, case study 10, engineer)

#### 4.3.3.3 It was a relief to stop

It was clear that continued employment was not the best option for some of the participants. There was evidence that working was having a negative impact on participants' wellbeing in a small number of the case studies. Participants reported that they experienced a high level of stress in their workplace, especially in the period before they received a diagnosis. An example is Myra in case study 16 who experienced high levels of stress in her job as an office manager of a school. She was struggling to cope with her work for a long period of time before she got her diagnosis, and this resulted in Myra walking out of the office in the middle of the day at one point and being off sick with work-related stress on two occasions. Myra felt that she had to continually make excuses for her mistakes or explain herself when she forgot something. This was difficult for Myra as she explains:

*I just put up, gave them the keys and walked out cause I thought I don't know what's wrong with me, but I know something's wrong with me but I couldn't tell you what it was.* (Myra, case study 16)

Myra's husband spoke about how he could see the effect working was having on Myra and they both agreed that given her circumstances, leaving work was the best thing for Myra.

*When she came in from her work she was dead stressed out every single day but when she stopped going to her work she was a lot better.* (Myra's husband, case study 16)

This was echoed in a number of situations where participants reported the increased stress they were experiencing and feeling relief at leaving work. For example, John in case study 1 felt relieved to leave work as he had been struggling with the symptoms of dementia for a number of months without a diagnosis. He had been making mistakes which resulted in him providing poor quality work and it was taking him much longer to complete his work. As he explained, he felt he couldn't take any more and was relieved to stop working.

*It was really the very understanding [line manager] and myself had a conversation about it and it was agreed that I would desist, that I would stop, though I have to confess it was a huge relief to me to be able to go 'oh, enough is enough'.* (John, case study 1)

The participants who experienced high levels of stress in their employment all had problems or delays in getting a final diagnosis of dementia. This was because they were confounded with misdiagnoses, for example depression, anxiety or the menopause. It is not clear whether these diagnoses were incorrect or co-morbid conditions which would further impact on work performance and coping abilities. It is clear from the case studies that continued employment is not appropriate



for everyone in every situation but for those who did manage to continue being active in paid or voluntary work, they perceived undoubted benefits.

#### 4.3.4 Theme 4 – Workplace perspectives

From the outset, it was realised that supporting a person with dementia may be challenging for the employer and their colleagues as well as for the person and their family. This theme will examine the perspectives of the employer and the specific challenges that they faced when they were supporting a person with dementia in the workplace.

##### 4.3.4.1 Doing the best we can

The employers included in the case studies all expressed a desire to want to do the best they could to support their employees. For most employers, this involved showing compassion to their employees and treating them with respect. For many, this stemmed from the personal relationships that had developed in the workplace as John's line manager in case study 1 explained:

*Yeah, I'm your line manager, but then at the same time I'm more concerned about your own personal wellbeing and obviously in doing that I'll do my role as a manager, but also your friend. So it's not that I crossed any bridges or anything. I adhere to what I'm supposed to do but I'm more interested in John you know. (John's line manager, College lecturer, Case study 1)*

However, for the employers it was not always easy for them to do the best they could for the employee as they had little knowledge of dementia and had not previously considered how to support an employee with dementia. None of the employers had previous experience of supporting an employee with dementia so there was a feeling that they were learning as they went. This meant that, at times, employers did not realise the most appropriate way to support an employee with dementia, and instead considered allowing them to take early retirement was the best thing for the employee.

*When clarification came through from all sources it was decided that there would be a final cut-off date where John could be discharged from the college in a manner that would allow him to gain the benefits of the illness. (John's line manager, case study 1, journalist/lecture)*

Whilst in some cases early retirement may have been the best option for the participant, in other s the participant was left feeling that their employer could have done more if they had a bit more understanding.

*Do they want to offer her something else? Do they know the implications that are going to go with that? Is it easier for them to just to pension her off? (Myra's husband, case study 16, office manager)*

The lack of knowledge of dementia was evident in a number of case studies as many workplace representatives spoke of the way dementia was portrayed in the media as being associated with older age so were not expecting it to be something that would affect people in the workplace.

*I have to say I always thought it was something that was associated with old age. I have heard of early onset but I thought it was quite rare. (Jack's line manager, Telephone engineer, Case study 6)*

However, in some of the case studies the employers did access dementia awareness training and this was highly regarded as the most useful resource by line managers and colleagues who were working with a person with dementia. The feeling was that a little knowledge helped them to understand much better the challenges the person was facing in the workplace and the type of support they may need.

*The awareness thing, it was a big eye opener you know. We just thought dementia was like forgetting things and that but we didn't realise likes of about the stairs. One of his jobs was that he had to go up the stairs to floor 16, so you got the lift to 15 and then you've got to go up the stairs, but Paul couldn't judge and it was something that we did notice that whenever he came to stairs he always seemed to hesitate and he was really concentrating you know and we weren't aware of that until the nurse came in. (Paul's line manager, case study 5, council officer)*

The format of the dementia awareness training varied greatly, in one case the participant delivered it herself, in others the participant's nurse came into the workplace to do it but only one company provided it as standard and in this case the line manager enrolled on the training after he found out about his employee's diagnosis. Whatever the format, dementia awareness training was valued as being very important for helping the employer do the best they could for their employee with dementia.

#### **4.3.4.2 Protecting business needs**

The case studies also highlighted the challenges employers face when trying to balance supporting their employee with dementia with running a successful business. This meant that when employers spoke about doing the best they could for their employee this was sometimes not in line with what was best for the business. Perhaps the starkest example of this was in case study 12 where Ken worked with his brother and they ran a shop which had been in the family for generations. Ken was diagnosed with Alzheimer's disease six years ago and his brother spoke about how he felt that the best thing for Ken was to continue working. Ken was not able to do many of the tasks he used to do, however his brother spoke about how his priority was keeping his brother active in the shop even if it was at a financial cost to the business. An example he gave was how they continue to ask Ken to collect the money from the tills at the end of the day:

*We didn't want to stop him doing it so we thought if we lose £20, £30, £100 what the hell does it matter you know, as long as he is keeping as, as, as much of his faculties going as he can but it, it's difficult you know cause your business head is saying you can't do this cause you're losing money here. (Ken's brother, case study 12, shop keeper)*

This case is unique because of the family relationship within the workplace and Ken's brother did admit that if it was not his brother then they wouldn't be able to continue supporting him to work.

*Well he would be gone I'm afraid [if he wasn't family]. You know, we really couldn't afford to, to keep it, unless you were getting some kind of grant or something from somewhere. (Ken's brother, case study 12, shop keeper)*

This case study is useful, however, in highlighting that there is a potential cost to supporting someone with dementia to continue working. This cost might be direct financial costs from mistakes

made by employees, such as described above, or costs from keeping the employee working at a lower level job but still on their full salary. An example of this was shown in case study 4 where Jim, who had worked as an electrical engineer, was working in the stockroom but was still paid his full engineer's salary. This presented a problem for his employer as they were not sure how best to address this issue with Jim. The employers were challenged because of changes in his personality which meant that Jim could become aggressive towards them when challenged. He refused to take a drop in salary because of the implications that would have for his pension and so the company felt that they had no choice but to terminate his employment because he was not competent to carry out his job. As the human resource manager reported:

*They were looking at terminating his employment at that time due to capability rather than due to ill health. (Jim's Human resource manager, electrical engineer, case study 4)*

In the end, Jim went on sick leave until his retirement date after his wife intervened in the situation; however, this was a very disappointing end for Jim to his working life.

Within the case studies, there was very little future planning of how to continue supporting their employee with dementia and what would happen when the employee's dementia progresses to a point when they are no longer able to work. When asked about preparing for the future or monitoring the person with dementia, very few of the line managers had thought about this. As the line manager in case study 6 said, it was something that he would think about addressing as a result of participating in the study.

*I think I need to have that conversation with him just to say you know how, if, if there is a deterioration, whether it just be temporary or a gradual, how am I going to be best sort of informed. How do I find that out because obviously there is a danger that people, I'm worried that it'll all crack and this is going to affect their performance, what, what you know is my, is my job at risk. (Jack's line manager, telephone engineer, case study 6)*

This lack of forward planning may reflect a lack of understanding about the progressive nature of dementia, but may also be related to the fact that it is potentially a difficult situation for a line manager to confront so they were not comfortable talking about it.

#### **4.3.4.3 Emotional impact on colleagues**

Another issue that was highlighted within the case studies was the impact that having a colleague diagnosed with dementia had on co-workers. This is something that employers also need to be aware of and support the rest of their employees as well as the person with dementia. Depending on the situation in each case study, there were differences in how the colleagues were affected. In some situations colleagues and line managers felt guilty that they had not spotted the signs of dementia sooner and felt like they may have been able to do something more to help the person if they had been more proactive. For example in case study 1, John's line manager spoke of how looking back he knew he had not taken the changes he noticed in John seriously and it was easier to explain them in other ways:

*I would have liked to have thought that I was the one that recognised it you know. It's quite a complicated little thing when you, when you get into the, the different scenarios that*

*could've transpired, did transpire etc. and how reflective you become and that after you look back you know.* (John's line manager, case study 1, lecturer)

For many colleagues there was the shock of discovering a close colleague had developed dementia. This was especially evident when the employee had never considered that dementia was something that might be present in the workplace.

*I was very upset, yeah. I was quite shocked you could get dementia so early on.* (Joan's colleague, case study 13, Head of business support)

This then led to some colleagues questioning their own cognition and worrying if they could develop dementia as they were of similar age.

*But it does concern me a little bit now that Rose has explained her situation and we actually have discussed, in the last two weeks, some of us older ones, as to what is actually just an age thing and a slowing down and what potentially could be the first signs of dementia.* (Rose's colleague, case study 9, Team leader)

There was also stress related to supporting a colleague with dementia, especially in the early stages pre-diagnosis when there was no clear understanding of why they needed support. An example of this was in case study 16 where the head teacher of the school had been supporting Myra who was the office manager to complete her job. This meant that at one point the head teacher was doing many of the office tasks as well as her role as head teacher. As Myra did not have a diagnosis at this point this caused tension in the relationship. When questioned about her mistakes, Myra became defensive as she couldn't explain why she had made mistakes. Although the head teacher can now look back and understand the stress that Myra was under, at the time her own health was affected and the relationship began to fail.

*That kind of affected my mental health a bit because you do start to think gosh is it me and am I being unfair and am I doing, so it's horrendous for Myra and it's devastating for her family but it did have a big impact on everybody else. It has been really, really difficult.* (Myra's line manager, case study 16, Office manager)

In other cases, there were close colleagues who were very good friends with the person with dementia and they were happy to support their friend in the workplace. However, now that their friend has left work, it has had a lasting effect on how they feel about their workplace. In both case study 5 and case study 15, the close friend felt that their friend had not been treated well. In case study 5, Paul's colleague felt that the other people he worked with had treated Paul badly and went out their way to make things difficult for him and laugh at him. As Paul's colleague worked closely with Paul and supported him in his job, he has lost his relationship with the other colleagues.

*I found that when I worked with him I wasn't happy with our colleagues, with the way the way they treated him you know, I thought it was quite, it wasn't right. They're doing it with me now, even now, so but if they can treat a man with Alzheimer's the way they treated him they can treat anybody that way.* (Paul's colleague, case study 5, council officer)

In case study 15, Alison's colleague felt that the way the organisation had treated Alison was unfair and that the management and senior colleagues had let Alison down. When Alison first started

experiencing problems she asked to reduce her hours and this was refused, following this the senior staff were instructed to monitor Alison's performance. Alison's colleague felt that they could see that Alison had a problem, but rather than doing something to support her they were trying to build a case against her for dismissal. This has resulted in her not trusting her employers and feeling resentful towards them.

*I'll never forgive them for that, you know. They should've been doing a bit more to help her.*  
(Alison's colleague, case study 15, maternity care assistant)

These two examples were the only two cases where the workplace representative was a close friend of the participant and continued to work at the organisation after the participant had left. It is not clear how common this relationship dynamic might be, although it is worth highlighting that close friends in the workplace may need more support and employers should be aware of this.

## 4.4 Case study key findings

### Box 4.1 Case study key findings

- 1) While there were many similarities in situations, each case study revealed a different experience of employment post diagnosis of dementia.
- 2) Continued employment post diagnosis of dementia is possible, but can be complex to manage and dependent on a number of factors.
- 3) The participants who continued employment felt there were many benefits of continued employment. These included helping them to manage their symptoms, keeping connected, financial security and improved overall wellbeing.
- 4) For some participants, continued employment was not possible, and for others the stress of continuing employment had a negative effect on their wellbeing. In these cases, the participants felt poorly supported for leaving work and adjusting to retirement.
- 5) Employers and colleagues need support in order to support a person with dementia in the workplace. This support may include dementia awareness training, accessible information and practical guidance.

## 5. Discussion

The aim of this project was to explore the employment related experiences of people with dementia or mild cognitive impairment (MCI), and the attitudes of employers and/or co-workers towards supporting people with dementia, in order to identify the potential for continued employment post diagnosis. Within the overall aim, five specific research objectives were set which are outlined below.

- 1) To assess the potential for continued employment for people with dementia or MCI post diagnosis
- 2) To ascertain how people with dementia or MCI cope in the workplace
- 3) To determine how employers manage challenges associated with employees who show signs of dementia/MCI
- 4) To ascertain the level of support that people with dementia or MCI require to retain employment, and whether employers and/or co-workers are able or willing to provide support of this nature
- 5) To inform public policy relating to the employment of people with progressive conditions

The research has addressed each of these aims. Aims 1-4 were fully addressed in the previous chapters presented here, while the fifth aim is addressed in the key recommendations and the dissemination strategy outlined later in this report.

As a feasibility study, it was conducted in three stages; a literature review to establish what was already known about dementia in the workplace; 16 key informant interviews with employment and healthcare professionals to understand how aware professionals were of dementia in the workplace and how they addressed the problem; and finally 17 case studies of people who developed dementia whilst still in employment were carried out to give a better understanding of the lived experience of developing dementia whilst still in employment. It was clear that there is a wide variation in the employment related experiences of people with dementia. Whilst some people are well supported in their employment, many find themselves in a difficult situation where they lose their job or have to take early retirement. The key findings from each of the chapters are presented below in Box 5.1.

#### Box 5.1 – Summary of key findings from chapters 2,3, and 4.

- 1) Six research papers were included in the literature review, of which only two had a specific focus on the employment of people with dementia.
- 2) No previous research has identified the potential for continued employment post diagnosis, thus little is known about the nature of the supports required to enable a person with dementia to continue employment post diagnosis.
- 3) The key informants from a healthcare background had more awareness of the issues surrounding dementia in the workplace than those from an employment background.
- 4) Supporting dementia in the workplace may be possible; however, each person with dementia will require different levels of support depending on the individual complexities of their situation.
- 5) There are a range of supports available to support people with disabilities continue or enter the labour market which could be adapted for use with people with dementia, however, to do this dementia must be conceptualised as a disability.
- 6) While there were many similarities in situations, each case study revealed a different experience of employment post diagnosis of dementia.
- 7) Continued employment post diagnosis of dementia is possible, but can be complex to manage and dependent on a number of factors.
- 8) The participants who continued employment felt there were many benefits of continued employment. These included helping them to manage their symptoms, keeping connected, financial security and improved overall wellbeing.
- 9) For some participants, continued employment was not possible, and for others the stress of continuing employment had a negative effect on their wellbeing. In these cases, the participants felt poorly supported for leaving work and adjusting to retirement.
- 10) Employers and colleagues need support in order to support a person with dementia in the workplace. This support may include dementia awareness training, accessible information and practical guidance.

### 5.1 Strengths and limitations

This is the first study to explore the potential for continued employment for people with dementia. Previous studies which report on the employment of people with dementia have not focused on the support required to continue working, instead focusing on first symptoms and problems experienced and the process of leaving work. (Chaplin and Davidson, 2014; Ohman et al., 2001) The present study is also the only study to include the views of three or more people in each case study to represent the views and experiences of the person with dementia, their family and their co-workers. This approach allowed for fuller understanding of each situation acknowledging that a person being diagnosed with dementia will also have an impact on the people close to them. However, a limitation is that it was not possible to include a workplace representative in every case study. There

were a variety of reasons for this, including the person with dementia having no contact with their previous workplace and there were challenges in some cases trying to engage with workplace participants with busy work schedules. Further to this, as the participants nominated their workplace representatives, this resulted more variability in the relationship workplace representatives had to the participants. This was positive in that it highlighted the differing impact of an employee developing dementia in the workplace on others, for example, close colleagues had a different perception to line managers, who had a different perception to human resource managers, however, because of the low numbers of each designation, drawing conclusions about certain aspects of workplace support was more challenging. For example, the impact of different line management strategies or the role of close workplace friends. Future studies may want to consider focusing on certain workplace relationships to ascertain the level of support required by both parties when a person develops dementia in the workplace.

Overall, this study has shown that continued employment post diagnosis of dementia is possible. However, the recruitment strategies used in this study means that much of the case study sample was self-selecting. This was evident in the fact that the majority of participants who responded to the social media advert for recruitment were still in work or had continued working post diagnosis. Indicating this strategy may only appeal to the people who had had a positive experience. Therefore the sample is not representative. However, as a feasibility study, the recruitment method was appropriate as it has highlighted that employment is an issue that people with dementia want to talk about and that it is possible to continue employment with the appropriate support. Future research should attempt to build on this foundation, revising recruitment strategies to identify how representative these experiences are of the wider population of people with dementia. A further limitation of the recruitment for the case studies was in the age range of the case study participants. It was hoped to recruit participants between the ages of 50 and 69 in order to capture the experience of people who may be working past 65 in line with the recent changes in government policy. This was not achieved and the sample age range was 50-66. Given that the changes to state pension age are very recent, it may be that few people are working past 65 at this time, however it is predicted that this will increase in the future. It may also be that people who develop the symptoms of dementia over the age of 65 are more likely to leave the workforce sooner, especially if they are experiencing other age related problems. Further research is required to examine the impact developing dementia may have on the employment of people over the age of 65 who wish to continue working.

## **5.2 Supporting continued employment post diagnosis**

Accessing a timely diagnosis was identified as important for continued employment post diagnosis. For many, delays in the diagnosis process led to long periods of under-performance in their job, increased stress and anxiety, and fear related to not understanding why they were not managing in work. There are many reasons why a diagnosis is delayed, however the longer the diagnosis is delayed, the more likely it is that the person will reach a crisis point in their work and will go off sick or will leave work before they have their diagnosis. Once a person had left the workplace, it was unlikely that they would return after they received their diagnosis, instead if they were still employed, the diagnosis was the trigger to start the process of early retirement due to ill health. This finding was echoed in both the key informant interviews and in the literature review, namely in the study by Ohman et al.(2001) which found that if a person with memory problems left work, they



were not likely to return. The problems associated with delays in diagnosis of dementia have been widely documented in the literature (e.g. Johannessen & Moller, 2011; Hayo, 2015; Mendez, 2006; Bakker et al., 2010) and while it is often documented that the first symptoms of dementia may emerge in the workplace, this is the first time that a delay in diagnosis has been highlighted as impacting on a persons' ability to continue employment. The UK Equality Act (2010) prohibits discrimination against people with disabilities. However, without a diagnosis of dementia, individuals will be unable to benefit from the provision of the Act.

Supporting a person with dementia to continue employment can be complex to manage. As well as a timely diagnosis, support is dependent on the attitude of the person with dementia and their family, the organisational culture in which they work, and finding the appropriate adjustments to their role to enable them to continue working. The key informants highlighted a number of external organisations and services which may have a role to play in supporting employees with dementia and/or their employers. However, the case studies found that very little support was sought from outside of the workplace, with the exception of the organisation's external occupational health providers who were not experienced in dealing with dementia. Much of this was due to employers and employees not being aware of the variety services which may be available. For example, vocational rehabilitation services may have a great deal of support and advice to offer. Vocational rehabilitation is primarily carried out by allied health professionals and aims to support people with health conditions to retain or return to employment. Although there is a lack of evidence relating to dementia in the workplace, vocational rehabilitation may be a valuable source of advice, guidance and good practice support to employers and employees, focusing on retaining ability rather disability.

Adopting a disability management approach to supporting employees with dementia may be successful. Employers who take a proactive attitude towards health and disability in the workplace are commonly more successful in retaining their employees who experience health problems. In these organisations, timely workplace adjustments, guided by vocational rehabilitation advice are most effective at supporting employees with health problems (Waddell et al., 2008). This approach appeared to be successful in a number of the case studies where organisations supported their employee to continue working, with the focus very much on what they can still do, rather than what they cannot. However, it is most commonly large organisations that have the resources and skills to adopt this approach, with many having internal occupational health services. There is little research evidence on how small and medium size enterprises support employees with health problems and disabilities, highlighting the need for more support and external services which can be accessed by these organisations (Waddell et al., 2008)

Many of the case studies did not take this approach, instead the focus was on what the person can no longer do and as a result that meant they could no longer continue working. Although in some occupations continued employment was not possible for example, for health and safety reasons, the majority of the participants felt they were able to continue working in some capacity but were not given the opportunity. There was a lack of understanding of dementia and for many their understanding was based on media representations of dementia being related to old age. Few people in the study had realised that dementia can affect people who are still in employment and found it a shock when a co-worker was diagnosed with dementia. Similarly, many did not appreciate that dementia is progressive, and therefore someone in the early stages of the disease may be able

to continue employment. If employers (and people with dementia) are not fully aware of the capabilities of the person with dementia and the supports available to them, then supporting continued employment appears somewhat impossible. Workplace education and dementia awareness sessions were found to be useful to those organisations that did support continued employment, however the structure, delivery and need for these varied greatly. Increased education about health conditions in the workplace can help to reduce stigma experienced, and promote positive attitudes and enable people to continue working with a disability.

### 5.3 Impact of continued employment

It was clear from the case studies that a person with dementia's employment situation had a substantial impact on their lives and that of their families. For many, there were the expected financial implications of leaving work before they had planned to. The interactions between loss of some or all of the participant's income, disruptions to the partner's or other family members' incomes, and delays in acceptance by the Department of Work and Pensions of the evolving and changed circumstances meant that household budgets usually came under significant and unplanned strain. Often these exacerbated all the other challenges of coming to terms with the diagnosis of dementia, generating further problems for the family.

As well as financial implications, there was a wider impact on the psychological, social and emotional wellbeing of the participants. Previous research has identified the voluntariness of retirement as an important determinant of wellbeing in retirement in the general population (Bender, 2012). Feeling forced into retirement leaves individuals feeling unprepared for change in lifestyle which comes with retirement, both financially and psychologically thus having a negative impact on their wellbeing. These findings are echoed in the current study, those participants who felt they had no control over leaving work, either because their illness meant that it was not possible to continue and no support was offered or because they felt pushed out by their employers were more likely to have financial problems and have fewer activities and social arrangements organised for their retirement. Adjusting to retirement with a diagnosis of dementia presents additional challenges for the person, their family and their healthcare workers, which has previously never been considered in the literature. Although the aim of this research was to investigate the potential for continued employment, this study has highlighted that continued employment is not possible or appropriate for every individual with dementia and appropriate support for leaving work and adjusting to retirement is just as important as supporting continued employment post diagnosis.

There were clear benefits of continuing employment to the participants and their families in this study. Much of this related to the idea that employment provided a challenge, a way of staying connected and feelings of doing something useful and worthwhile. A person's sense of self is closely tied to their occupation, and their perception of who they are is closely tied to what they do (Ross and Buehler, 2004). Thus, when a person loses their job unexpectedly, they can suffer a loss of identity or sense of self. Furthermore, preserving identity in early stage dementia is thought to be linked closely to 'being valued for what you do' and 'being valued for what you are' (Steeman et al., 2013). Being diagnosed with dementia puts a person at risk of being seen as having a spoiled identity; this may be further compounded by losing their job. A spoiled identity is defined as an identity which results in a person being stigmatised. This is where an aspect of a person's identity is not perceived as 'normal' for example, having a diagnosis of dementia and as a result, they struggle to adjust their social identities and can become stigmatised in society (Goffman, 1963). How people

respond to this stigma is important for their continued wellbeing. Withdrawing from society or 'hiding' as Goffman refers to it, is a common way of dealing with stigma, but can lead to isolation, anxiety and depression. Other responses to stigma resulting from a spoiled identity are listed as using it as a learning experience, highlighting other skills and abilities to compensate or joining self-help groups and clubs to foster a sense of belonging. Evidence of all of these things were evident in the case studies, for some, losing employment compounded the sense of stigma and their response was to withdraw from their previous social lives and activities, which had a negative impact on wellbeing. Others however, used their continued employment or other engagements as a more positive way of addressing their spoiled identity, allowing them to stay engaged within their community and feel supported and valued.

Engaging in meaningful activity has important therapeutic benefits for people with dementia. There are many different forms of meaningful activity, and these vary depending on the age, gender and interests of the person with dementia. Some examples include gardening, reminiscence programmes, art classes or intergenerational activities. For younger people with dementia, the importance of work has been recognised and there have been examples of day schemes set up to allow younger people with dementia to volunteer in a workplace in a safe and supported environment (Robertson et al., 2013; Kinney et al., 2011). However, these schemes are expensive to run and for many families are seen as substitute for day care, which means that they may not be available or suitable for all people with dementia. This study has shown that when well supported many people with dementia can continue working, and by continuing in a job they have done for many years they are retaining their skills and continuing to contribute economically and socially to society. This links to the emergent literature which promotes active ageing as a framework for promoting healthy ageing focuses on the importance of keeping engaged in the community, both economically (work) and socially (maintaining relationships/volunteering/activities) (Boudiny, 2013). Little has been written about the concept of active ageing out with what is considered 'healthy ageing' however it has been recognised that ways of keeping engaged can vary with ability. Although never previously considered in the literature, the findings of this study suggest that active ageing is a relevant concept for people with dementia and that for those for whom it is possible, supporting continued employment may have a lasting positive impact on their wellbeing.

The case studies have supported the prior expectations that the employment institutions would be very important in determining post diagnosis experiences. The examples of highly skilled professionals being unable to continue in high status employment are similar to those in the lower end of the labour market – skills, human capital, experience degrade and disappear through the illness with very limited realistic prospects of redeployment so that economic inactivity follows, almost inevitably. For those engaged with larger employers with strong and diverse internal labour markets, unionised with well-defined and progressive terms and conditions, there are instances of movement within the organisation and greater protection from redundancy and retirement.

Counter examples of continuing employment in small and micro enterprises and movement out of large organisations confirm the significance of individual presentations of dementia, of the attitudes and behaviour of line managers and employers, professional reactions, etc. but there are sufficient indications here to suggest that policies, strategies and support for employers needs to recognise those contextual dimensions of their employment.

For those released into inactivity, there are major obstacles to reengaging with employment – the highly competitive, flexible labour market where almost all posts require candidates to have general skills will tend to exclude those with unstable and failing human capital. Therefore, where desirable and appropriate, retaining those with dementia in the labour market is optimised by supporting them and their employers to keep them with that same employer.

Where leaving employment becomes necessary, desirable, appropriate or inevitable (and any and all these may apply for any particular individual given the circumstances peculiar to them), then there is a greater need for agencies and departments to address issues around benefits, pensions, financial management, possibly volunteering, part-time and casual work, etc.

A significant but neglected area that needs attention concerns the labour market impacts on partners and other family members. Quite rightly, there has been extensive research and policy prescriptions concerning childcare and the implications these have for carers' abilities to participate in the labour market. Interest, research and strategies on caring for older adults and those with limiting long-term illnesses is less well established and funded. As the incidence of older workers having caring responsibilities for aged parents and other relatives grows, so the issues revealed by this study will become more critical and demand attention. While many of the challenges remain hidden within the immediate family, the costs to families and society of the failure to recognise and offer support in managing their lives, work and incomes will be unrecorded, underestimated and will continue to grow.

## 5.4 Policy implications

It is clear that employment is/was a significant issue for the participants in this study when they were diagnosed with dementia. However, because younger people with dementia represent a small percentage of the population with dementia, addressing the issues surrounding dementia in the workplace has not received any specific attention in policy documents, although many recent policy changes may be positive for supporting people with dementia in the workplace. However, given that people will be working until later live in the coming years and there are estimated 38,000 people in the UK under the age of 65 with dementia, employment is an issue which has to be addressed for people with dementia. There are a number of existing policies which may be of benefit to this group of people, however, increased education is required for employers and employees to understand the implications of dementia and how these policies may relate.

The recent policy changes in the UK relating to the removal of the default retirement age and the increase in state pension age has meant that the UK Government has recognised the issues of an ageing workforce with the publication of the document Fuller Working Lives (2014). The aim of this is to understand and identify ways to support people to remain in work until state pension age. It highlights health problems, disabilities and caring responsibilities as three of the main reasons for early labour market exit and identifies support that is available to prevent this. This includes campaigns to change attitudes towards disability and older workers and ensuring small and medium size businesses have access to occupational health services. These initiatives may be of benefit to employees with dementia, however for this to happen, dementia must be perceived as a disability. The new 'Fit for Work' campaign which offers occupational health assessments to anyone who has been off work sick for more than 4 weeks has launched in the UK (<http://www.fitforworkscotland.scot/>). If occupational health services are well informed about

dementia and understand the types of support they may require, this may be a useful resource for helping to identify, diagnose and support an employee with dementia. As a result of funding this study, The Alzheimer's Society has recognised that dementia will be increasingly something that employers will encounter in their organisations, and have produced an employers' toolkit which outlines how best to support an employee who develops dementia. This aims to raise awareness of dementia amongst employers and provide practical information about the types of support which may be useful and signposts for further information.

The UK government has launched the next phase of the Prime Ministers challenge on dementia in early 2015. The Scottish Government launched their second dementia strategy in 2013 and is currently working towards the third strategy. These initiatives mean that the standard of care for people with dementia is improving and significant issues which face people with dementia are beginning to be addressed. There is a current focus on timely diagnosis of dementia. For example, the Scottish Government have committed to supporting accurate and timely diagnosis of dementia and since the first dementia strategy in 2010 the Scottish diagnosis rate has risen to 65% (The Scottish Government, 2013). This is a positive change; however, the exact diagnosis rates for early onset dementia are unclear. As mentioned previously, for a person to continue employment, getting a timely diagnosis allows them to access the appropriate supports and gives them the protection of the Equality Act 2010. The Scottish Government have also committed to provide a minimum of one year post diagnostic support for every person diagnosed with dementia. This could be a valuable asset to a person with dementia who is still in employment; provided that the professional delivering the support has an understanding of employment issues and is able to signpost the person on to the appropriate services.

Nationally, work is being carried out to improve dementia awareness within the general public with the Dementia Friends initiative led by the Alzheimer's Society (<https://www.dementiafriends.org.uk/>) and Alzheimer Scotland (<http://www.dementiafriendsscotland.org/>). This may be beneficial to employers by raising awareness and understanding about dementia, meaning that if they are faced with an employee who has dementia they are better equipped to support them.

## 5.5 Recommendations

A number of recommendations have arisen from this research. These recommendations aim to inform the development of practical support for people with dementia in the workplace and their employers, shape future research and influence policy related to continued employment for people with dementia post diagnosis. The recommendations are shown in box 5.2:

### Box 5.2 – project recommendations

- 1) An enhanced dissemination strategy for this research is required in order to raise awareness of the issues surrounding dementia in the workplace to the general public and in particular with employers.
- 2) Resources for employers, employees and other key stakeholders need to be developed which provide accessible information on relevant employment law.
- 3) Practitioners who work with individuals from the first point of contact through to post diagnosis of dementia need to consider the implications for employment and the potential financial and social impacts on the individual.
- 4) The post diagnostic framework needs a review of the implications of employment issues for individuals with dementia, in particular work with national work and pension agencies to ensure timely access to appropriate benefits, pensions and supports.
- 5) Further research is required to fully understand the problems relating to the employment of people with dementia. In particular, research is required to:
  - a. Strengthen the evidence for workplace supports identified in this study,
  - b. Further investigate the potential impact employment has on the lives of people with dementia, with a focus on potential gender differences
  - c. Understand how an employee can be managed over time in the workplace as their dementia progresses.
- 6) Reflecting on the recent changes in the employment of older people and the changes in state pension ages across Europe, we urgently need a stronger understanding of the international landscape for employment of people with dementia.

## 5.6 Conclusion

The Dementia in the Workplace study has been the first study in Europe to fully explore the experiences of people with dementia in employment and investigate the potential for continued employment post diagnosis. The study has revealed the profound impact employment-related issues have on the lives of people with dementia and their families. Further to this, a person being diagnosed with dementia whilst still in the labour market has a wider impact on their colleagues, line managers and employers which also need to be considered. Although early onset dementia creates quite specific effects, there are lessons more generally for national work and pension agencies, employers and advocates as to how and when they should be interacting with individuals and families. Given the increases in state pension age and the focus on working into later life, the insights this research offers therefore extends well beyond early onset dementia and confirms the need for further work on the labour market implications for people with progressive illnesses such as dementia. In order to achieve this and ensure the appropriate support for people with dementia, their families and employers, investment in further research and appropriate policy responses are urgently required.

## 6. How well were the objectives met?

We have met all five of the research objectives set out in chapter 1. We have indicated which objectives have been met at the start of each of the chapters reporting on the findings of the literature review, the key informant interviews and the case studies.

### Objectives of Research

1. To assess the potential for continued employment for people with dementia or MCI post diagnosis.

*This was met by the findings of the literature review, the key informants and the case studies. It was found that there is potential for people with dementia to continue employment post diagnosis, however further research is required to develop a deeper understand of the support required.*

2. To ascertain how people with dementia or MCI cope in the workplace.

*This objective was met by the findings of the case studies by highlighting the coping strategies people used in their employment and the efficacy of these.*

3. To determine how employers manage challenges associated with employees who show signs of dementia/MCI.

*This objective was met by the findings of the case studies. Employers interviewed as part of the case studies described the challenges they faced and this is fully reported in the theme 4 of the cross case analysis.*

4. To ascertain the level of support that people with dementia or MCI require to retain employment, and whether employers and/or co-workers are able or willing to provide support of this nature.

*This objective was met by the findings of the literature review, key informant interviews and the case studies. The level of support needs to be considered on a case by case basis, however some people with dementia may require a high level of support to stay in employment, and for others, they may require support with leaving employment.*

5. To inform public policy relating to the employment of people with progressive conditions.

*This objective has been met through the recommendations made in this report and with the ongoing dissemination of the findings of this research.*



## 7. Publications and dissemination

### 7.1 Publications

Ritchie, L., Banks, P., Danson, M. and Tolson, D. (2015) Dementia in the Workplace: a review. *Journal of Public Mental Health*

Danson, M., Ritchie, L. Banks, P. and Tolson, D. Ageing, health and employability in urban labour markets. (under review)

#### **Planned publications:**

Working title - 'Dementia in the Workplace: The potential for continued employment post diagnosis' – paper reporting on findings from case studies.

Working title - 'Age matters: Early-onset dementia and the reality of social construction' – theoretical paper focusing on the social construction of dementia and the implications in the workplace.

### 7.2 Conference presentations

Ritchie, L., Tolson, D. and Danson, M. 'Work keeps me well' the benefits of continued employment post diagnosis. At the 25<sup>th</sup> Annual Conference of Alzheimer Europe in Ljubljana, Slovenia 2<sup>nd</sup>-4<sup>th</sup> September 2015

Banks, P., Ritchie, L. Danson, M. and Tolson, D. 'Dementia in the workplace: the potential for continued employment post diagnosis.' at the 24th Annual Conference of Alzheimer Europe in Glasgow, Scotland from 20-22 October 2014.

Ritchie, L, Banks, P., Danson, M. and Tolson, D. 'Dementia in the workplace: the potential for continued employment post diagnosis.' at the British Society of Gerontology annual conference 2014, University of Southampton 1st -3rd September 2014.

Banks, P, Tolson, D, Ritchie, L and Lau, C Life and work after diagnosis. At the Alzheimer Scotland Innovation, Research and Technology in Dementia. Dementia Awareness Week Conference 2014. Crowne Plaza Hotel, Glasgow 6th June 2014.

Banks, P. and Ritchie, L. Challenges in the Workplace. At the 7th Annual Scottish Conference on Dementia in Younger Adults, Apex Hotel, Edinburgh on the 25th October 2013.

## 7.3 Other dissemination

### Blog posts:

The potential for continued employment after a diagnosis of dementia.

Young Dementia UK, Newsletter, January 2015

<http://content.yudu.com/Library/A3doay/YoungDementiaUKJanua/resources/index.htm?referrerUrl=http%3A%2F%2Ffree.yudu.com%2Fitem%2Fdetails%2F2739664%2FYoungDementia-UK-January-2015-Newsletter>

Webpage

<http://www.youngdementiauk.org/potential-continued-employment-after-diagnosis-dementia>

Dementia in the workplace: the potential for continued employment post diagnosis, Guest blog, Alzheimer Scotland, Let's talk about dementia blog. 16<sup>th</sup> November 2014

<https://letstalkaboutdementia.wordpress.com/2014/11/06/dementia-in-the-workplace-the-potential-for-continued-employment-post-diagnosis/>

### Short articles:

"Dementia in the Workplace: the potential for continued employment post diagnosis" included in Disability in the workplace - training, capability assessments and support. Briefing paper for the Westminster employment Forum

### Information stands:

Younger people with dementia: living well with your diagnosis launch. Thistle Hotel, Glasgow on the 20<sup>th</sup> March 2014

The Journey to Work: Work is a Health Outcome. National Allied Health Professionals Vocational Rehabilitation event. Grand Central Hotel, Glasgow on the 3<sup>rd</sup> April 2014.

### Training:

'Dementia in the Workplace' training for the Lanarkshire Young Onset Dementia Team away day, 20<sup>th</sup> October 2015.

'Dementia in the Workplace' Alzheimer Scotland Helpline advisors training session, 15<sup>th</sup> November 2014.

## 7.4 Media coverage

In press: 'Dementia in the Workplace' for Ask the experts feature in InCommerce, the magazine of the Lanarkshire Chamber of Commerce.

Research is identifying how employers can help people with dementia stay in work for longer, Living with Dementia magazine, July 2015

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=3038&pageNumber=3](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=3038&pageNumber=3)

**Press release** 'Support call for employees diagnosed with dementia' Issued 19<sup>th</sup> February 2015

Resulting press coverage:

- Call to be more dementia-friendly. Press Association, 19/02/15
- Support call for employees diagnosed with dementia. Bloomberg business, 19/02/15
- M2 presswire 19/02/15
- Charity news 20/02/15
- Dementia sufferers 'can work for years'. The Metro, 20/02/15
- Scots are less likely to work past state pension age than other brits – The Herald, 20/02/15
- New UK dementia plan will tackle 'greatest challenge' - The ,i 21/02/15
- Hidden misery of thousands of Scottish workers struggling to cope with dementia - Sunday Herald, 15/03/15
- Broadcast interview – BBC radio Scotland 23/02/15 Piece regarding dementia in the workplace which features interview of Louise Ritchie of UWS. BBC iPlayer <http://www.bbc.co.uk/programmes/b053c23z>

Employers must become aware of dementia in the workplace. The Conversation, 8<sup>th</sup> June 2014  
<https://theconversation.com/employers-must-become-aware-of-dementia-in-the-workplace-28125>

The Herald – Research bid to help dementia sufferers stay in jobs 16/1/14

Paisley daily express – University leads the way in the workplace. Research could help those with dementia keep their jobs. 16/1/14

## **8. Any other output or impact from the project**

As a result of the project, the University of the West of Scotland has committed to becoming a dementia friendly employer.

The project was shortlisted as a finalist for the Potential for Impact Category at the NMAHP Research Awards held at The Scotsman Hotel Edinburgh, 28<sup>th</sup> October 2015.

## **9. Future plans**

The research team will continue to work together applying for research funding to develop the research area in line with the recommendations outlined above. We intend to apply for a dissemination grant from the Alzheimer's Society in order to develop an enhanced dissemination strategy to raise public awareness of the issues surrounding the employment of people with dementia. We are also in the early stages of preparing a research proposal with colleagues at the University of Bradford's School of Management focusing on workplace interventions to support employees with dementia. Dr Louise Ritchie, the research fellow on this project was appointed to the post of Lecturer in Dementia (Research) with the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland.

## **10. What was your experience of working with Research Network volunteers?**

We have found the experience of working with the Research Network volunteers to be an excellent method of continued patient and public involvement in the research in addition to the input from our project reference group. The feedback and input from the volunteers has been useful and encouraging. However, we would have valued more guidance on what to expect from the input of the volunteers and how involved they would like to be. This was something that was discussed on a number of occasions at the volunteers' meetings and they themselves were unsure of what would be expected.

## 11. Lay Summary

### 11.1 Introduction

As in other European countries the number of older people in Scotland is increasing. Although longer life is a good thing, older age often includes a range of challenges including a growing number of people with long term conditions, one of which is dementia. Recent figures suggest that approximately 84,000 people have dementia in Scotland; this number is expected to double within 25 years. Figures for the UK as a whole show a similar pattern. The recent rise in the state pension age and the removal of compulsory retirement at 65 will result in more people with long term conditions being economically active; however, because dementia is usually thought of as something that happens to older people, little attention has been paid to the opportunities for employment. Not much is known about the experiences of people with dementia who are, or would like to be, working.

Allowing people to work longer may bring financial benefits to individuals and their families, as well as the economy and businesses. However, an increase in the number of older people in employment is likely to have costs as well as benefits. Research shows that there are age-related changes which could affect performance in the workplace. More people working in later life will result in a higher number of people with long term conditions in employment and, while the impact of some long term conditions, particularly those associated with physical disabilities, can be reduced by use of technology and/or a change in role, continued employment for people with dementia poses specific difficulties for those affected and their employers. The changes in pension age mean older people may find their work being monitored more closely as employers can no longer assume that they will leave at 65. However, employers have been found to have little understanding of the impact of increasing age and age-related conditions.

### 11.2 Aims and objectives

The overall aim of this project was to explore the employment related experiences of people with dementia or MCI, and attitudes of employers and/or co-workers towards supporting people with dementia, in order to identify the potential for continued employment post diagnosis.

Five objectives arose from the study aim:

- 6) To assess the potential for continued employment for people with dementia or MCI post diagnosis
- 7) To ascertain how people with dementia or MCI cope in the workplace
- 8) To determine how employers manage challenges associated with employees who show signs of dementia/MCI
- 9) To ascertain the level of support that people with dementia or MCI require to retain employment, and whether employers and/or co-workers are able or willing to provide support of this nature
- 10) To inform public policy relating to the employment of people with progressive conditions

The research was conducted in three stages, firstly a review of the existing literature, followed by key informant interviews, and finally case studies of people with dementia who had been employed when they received their diagnosis were carried out. The remainder of this report will report the

findings of each of these aspects in turn, concluding with a short discussion of the implications of these findings for future policy, practice and research.

### **11.3 Literature review**

The aim of the literature review was to establish, from a range of perspectives, the potential for continued employment post diagnosis for a person with dementia, and the nature of support that would enable/enables people with dementia or mild cognitive impairment (MCI) to retain employment. The review highlighted that there is a lack of research investigating the issues relating to the employment of people with dementia. Only six research papers were included in the literature review, and of these papers, the focus was very much on people with dementia leaving employment following their diagnosis rather than attempting to explore the potential for continued employment. No previous research has identified the potential for continued employment post diagnosis, thus little is known about the nature of the supports required to enable a person with dementia to continue employment post diagnosis.

### **11.4 Key informant interviews**

Key informant interviews were carried out in order to help to shape and inform the development of the case studies. Key informant interviews are defined as conversations with people who are deemed to have a level of expertise in the topic of interest. As there is no known expert on the issues of dementia and employment, key informants were chosen from a range of backgrounds to include expertise on dementia, employment issues, government policy, and support organisations. The participants in the key informant interviews are shown in table 11.1 below.

Each key informant interview was recorded and transcribed with the participants' permission. The transcripts were analysed using a method of thematic analysis.

The main findings from the key informant interviews highlighted that little is known about the issues surrounding dementia in the workplace but that continued employment post diagnosis could be possible with the correct support. The key informants from a healthcare background had more awareness of the issues surrounding dementia in the workplace than those from an employment background. This was because the healthcare professionals had much more experience of supporting people with dementia, therefore had supported people with employment issues. Key informants with expertise in employment had never before supported an employee with dementia and had little awareness of the challenges associated with an employee developing dementia.

The key informants felt that supporting a person with dementia in the workplace may be possible; however, each person with dementia will require different levels of support depending on the individual complexities of their situation. These complexities included; the time it takes to get a diagnosis, the type of dementia, the type of job the person does, the support available to them and the insight the person has into their abilities.

Table 11.1 key informant interviewees.

No.	Role	Expertise
1	Senior Civil Servants (Scottish Government)(2)	Government policy relating to dementia
2	Consultant in Old Age psychiatry.	Dementia
3	Depute director of Human Resources	Employment policy
4	Senior Nurse, Younger Adults with Dementia.	Early onset dementia, supporting people to continue working
5	Consultant Clinical Neuropsychologist. (2)	Dementia
6	AHP Lead for Vocational rehabilitation.	Mental health vocational rehabilitation.
7	Consultant in Old Age Psychiatry.	Dementia, patients who have been/are in employment.
8	Consultant Psychiatrist.	Early onset dementia, patients who have been/are in employment.
9	Access to Work advisor, Department of Work & Pensions	Disability and employment
10	Project Manager at Healthy Working Lives.	Employer support
11	General Practitioner (GP)	General health
12	Alzheimer Scotland Link worker	Dementia, supporting people to continue working.
13	Person with Dementia	Experience of being in employment when diagnosed with dementia.
14	Trade Union Representatives(2)	Employee support and disability specialist.
15	Senior Disability Manager	Disability and employment.
16	Head of Human Resources	Employment policy

There are a range of supports available to support people with disabilities continue or enter the labour market which the key informants highlighted. These included the Access to Work scheme and other NHS based work rehabilitation services. These services could be adapted for use with people with dementia, however, to do this dementia must be conceptualised as a disability rather than an illness. The key informants felt that workplace dementia awareness training may be useful for employers to understand more about dementia and highlight that a person with dementia does retain many skills and could continue working, if they wished to and had the appropriate support.

## 11.5 Case studies

Seventeen case studies were carried out in the final phase of the research. Each case study focused on a person with dementia who was still employed or had been employed in the previous 18 months and involved interviews with the person with dementia, a family member and a workplace representative. The inclusion criteria for the case studies are shown below:

### People with dementia

- Aged 50-69
- Diagnosis of dementia or MCI and aware of diagnosis
- Employed, self-employed, or stopped paid work within the previous 18 months
- People with alcohol related dementia must have a recent record of stable employment
- Be willing to identify additional case study participants
- Understand what taking part in the project would involve and give consent

The recruitment of additional case study participants was guided by the person with dementia. They were asked to nominate additional participants to inform the case study based on the following criteria:

### Other participants

- Key informants from participants' current or previous workplace, family members, NHS, local authority or third sector staff
- Knowledge of participants' work related experiences

Data collection involved one to one interviews with the person with dementia or MCI, family members, a representative from the workplace, and other people identified by the person with dementia. Interviews used visual prompts to help the discussion.

Seventeen case studies were recruited from a range of backgrounds. Table 11.2 below provides information on each case study. All participants' names have been changed to protect anonymity.

The cross case analysis of the case studies revealed that while there were many similarities in situations, each case study revealed a different experience of employment post diagnosis of dementia. Eight people continued working post diagnosis in some capacity, while nine left employment when they received their diagnosis.

The case studies concluded that continued employment post diagnosis of dementia is possible, but can be complex to manage and dependent on a number of factors. These included getting a timely diagnosis, which means support can be accessed quickly and reduce the time that people were struggling at work without knowing what was wrong and they type of job the person did. Some jobs were easier to make adjustments to as they could easily adapt their roles in line with their capabilities, such as in the case of the Head of Business Support. This was in contrast to other occupations, for example the electrical engineer and HGV driver where continued employment was not possible in that role because of health and safety concerns.



Table 11.2 Case study participants

No.	Name	Occupation	Age	Gender	Diagnosis	Date of diagnosis	Continued employment post diagnosis?	Recruitment method
1	John	College Lecturer	56	Male	Frontotemporal dementia	Retired	No	Direct contact
2	Joe	Handy man	53	Male	Mild cognitive impairment	Employed	Yes	Healthcare referral
3	Michael	HGV driver	50	Male	Frontotemporal dementia	Retired	No	Healthcare referral
4	Jim	Electrical Engineer	66	Male	Alzheimer's disease	Retired	No	SDCRN
5	Paul	Council Officer	62	Male	Alzheimer's disease	Retired	Yes	Healthcare referral
6	Jack	Telephone Engineer	54	Male	Frontotemporal dementia	Employed	Yes	Social media
7	Edward	Judge	63	Male	Dementia	Retired	No	Social media
8	Anna	Nurse	62	Female	Alzheimer's disease	Retired	No	Social media
9	Rose	Team leader	58	Female	Alzheimer's disease	Employed	Yes	Social media
10	Chris	Mechanical Engineer	55	Male	Vascular dementia	Retired	Yes	Healthcare referral
11	Tom	Cinema Projectionist	63	Male	Corticobasal degeneration	Retired	Yes	Social media
12	Ken	Shop owner	62	Male	Alzheimer's disease	Employed	Yes	Healthcare referral
13	Joan	Head of Business Support	58	Female	Alzheimer's disease	Employed	Yes	Direct contact at event
14	Mary	Office Manager	55	Female	Alzheimer's disease	Unemployed	No	Healthcare referral
15	Alison	Maternity Care Assistant	52	Female	Alzheimer's disease	Sick leave (awaiting retirement)	No	Healthcare referral
16	Myra	Office Manager	53	Female	Alzheimer's disease	Sick leave (awaiting retirement)	No	Healthcare referral
17	Steve	Safety inspector	57	Male	Frontotemporal dementia	Retired	No	Healthcare referral

The participants who continued employment felt there were many benefits of continued employment. These included helping them to manage their symptoms, keeping connected, financial security and improved overall wellbeing. For some participants, continued employment was not possible, and for others the stress of continuing employment had a negative effect on their wellbeing. In these cases, the participants felt poorly supported for leaving work and adjusting to

retirement. Leaving employment before planned retirement age had a significant impact on the lives with people with dementia and their families. Some participants had serious financial problems as a direct result of having to leave work, while others found themselves socially isolated because of the strong links between their social lives and their workplace. Many of the participants, in particular the male participants who did not continue working, found adapting to the change in lifestyle that came with early retirement difficult. Many participants found the process of leaving work difficult and involved lots of uncertainty as they felt the control over the decision whether they could continue work was in the hands of their employers rather than their decision. This decision often took a number of months when the participants were left at home unsure of what the outcome would be and when they would know and be able to move on with their lives.

From the perspectives of the workplace, there were a number of findings which related to impact on the employers and colleagues of the person with dementia. Firstly, there was a strong emotional impact on employers and colleagues when they discovered their colleague had been diagnosed with dementia. Much of this was shock, fear, and guilt of not being able to spot the symptoms sooner and support them further. For the case studies where the colleagues had been close friends with the participant, if they perceived their friend had not been supported well in the workplace, it changed their feelings about working there as well and meant even when their friend had left employment they experienced challenges as a result of their close relationship. The case studies highlighted that employers and colleagues may need extra support in the workplace. This support may include dementia awareness training, accessible information and practical guidance. Line managers of people with dementia always expressed a desire to do the best they could by the employer and tried to get what they perceived was the best outcome for their employee with dementia. However, there was a lack of understanding about dementia and no employer had previous experience of supporting an employee with dementia so employers did not access any external support and many employers appeared to be of the opinion that leaving work was the best thing for their employee, even though the employees had expressed a desire to continue working in some capacity.

## 11.6 Discussion

Overall, the dementia in the workplace study has identified that continued employment post diagnosis of dementia is possible, although could be complex to support. The supports required to continue working will depend on the type of job a person does, the insight they have into their symptoms and the culture of the organisation they work in as to whether they have the resources to support them. The Equality Act 2010 states that employers have a responsibility to make reasonable adjustments to a person with a disability's workplace or to their job description in order to support them to continue employment. However, this study has highlighted a lack of understanding about dementia and therefore a challenge to employers and people with dementia is agreeing what a reasonable adjustment to their workplace might be. This study has highlighted that allowing flexible working (including home working) and a reduction in allocated duties may be two important adjustments, as well as giving all information in written format and creating a quiet space for them to work with minimal distractions. It is also important to highlight the lack of support that was available for people with dementia who left employment and therefore any future work should also consider how to support people with dementia leaving employment as well as continuing employment.

This study recommends that further work is carried out in order to fully understand the usefulness of these adjustments, as well as understanding more about how an employee is supported in the workplace as their dementia progresses. The public awareness of dementia needs to be raised including within employers and employment related agencies so they are aware of the challenges they may be presented with in the future and how best to support their employees.

In conclusion, this project has highlighted that employment has a big impact on the lives of people with dementia and those involved with supporting them, including their families and their employers. This study was the first to fully explore the experiences of people with dementia in employment and has laid the foundations to shape policy and develop future research to benefit the lives of people with dementia and their families.

## 12. References

- Adams, J., Stamp, E., Nettle, D., Milne, E. and Jagger, C. (2015) 'Anticipated survival and health behaviours in older English adults: cross sectional and longitudinal analysis of the English Longitudinal Study of Ageing', *PLoS ONE*, 10(3):e0118782. DOI:10.1371/journal.pone.0118782
- Adriansen, H.K. (2012) Timeline interviews: A tool for conducting life history research. *Qualitative Studies*, 3(1), 40-55.
- Alzheimer Disease International (2012). *National Alzheimer and Dementia Plans Planned Policies and Activities: Early Detection, Access to Diagnosis, and Stigma Reduction*. Alzheimer Disease International. Available at <http://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf> last accessed 23/4/14
- Alzheimer's Australia. (2007) Exploring the Needs of Younger People with Dementia in Australia. [Online] Available: <http://www.fightdementia.org.au/services/further-reading-and-resources.aspx> [Accessed 17/4/14, 09:49]
- Alzheimer's Society (2014) Statistics.  
[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=341](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341)
- Baxter, P. and Jack, S. (2008) Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *The Qualitative Report*, 13 (4) 544-559.
- Bender, KA. (2012). An analysis of well-being in retirement: The role of pensions, health, and 'voluntariness' of retirement. *Journal of Socio-Economics*, 41(4), 424-433
- Bentham, P. and La Fontaine, J. (2007) Service Development for Younger People with Dementia, *Psychiatry*, 7(2), pp. 84-87
- Berney, L. and Blane, D. (2003) The Lifegrid method of collecting retrospective information from people at older ages. *Research Policy and Planning*. 21(2), 13-22.
- Boudiny, K. (2013). 'Active ageing': from empty rhetoric to effective policy tool. *Ageing and Society*, 33, pp 1077-1098 doi:10.1017/S0144686X1200030X
- Brooks, L., G. and Loewenstein, D. A. (2010) Assessing the progression of mild cognitive impairment to Alzheimer's disease: current trends and future directions. *Alzheimer's Research & Therapy*. 2, 28.
- Burns, J. M. C. (2010) Cross Synthesis and Analysis, in A. J. Mills, G. Durepos, and E. Wiebe (eds) *Encyclopedia of Case Study Research*, pp265-266.
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3(2), pp77-101.
- Brechin, D. (2004) Dementia in the Workforce. *Science and Public Affairs*.  
[http://www.britishtscienceassociation.org/NR/rdonlyres/F1FD95BE-DBF6-4A8D-8E51-020B8C53F08C/0/4106\\_SPA\\_March\\_04.pdf](http://www.britishtscienceassociation.org/NR/rdonlyres/F1FD95BE-DBF6-4A8D-8E51-020B8C53F08C/0/4106_SPA_March_04.pdf)
- Brown, R., Danson, M. and Novotny, V. (2008) 'Older people and employment in Scotland: policy trends and current policy approaches', *Scottish Affairs*, 65, pp 67-86.

- Chaplin, R. and Davidson, I. (2014) What are the experiences of people with dementia in employment? *Dementia*. DOI: 10.1177/1471301213519252
- CIPD (2006) Talent Management: Understanding the Dimensions, <http://www.cipd.co.uk/hr-resources/research/talentmanagement-understanding-dimensions.aspx>
- Chaston, D. (2010) Younger adults with dementia: a strategy to promote awareness and transform perceptions. *Contemporary nurse: a journal for the Australian nursing profession*. 34 (2), pp.221-229.
- Cox, C. B., and Pardasani, M. (2013) Alzheimer's in the workplace: a challenge for social work. *Journal of gerontological social work*. 56 (8), pp.643-656.
- Crawford, J. O., Graveling, R. A., Cowie, H. A. & Dixon, K. (2010) The health safety and health promotion needs of older workers. *Occupational Medicine*. 60, 184-192.
- Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A. and Sheikh, A. (2011) The case study approach. *Medical Research Methodology*. 11, 100. doi:10.1186/1471-2288-11-100
- Danson, M., and Gilmore, K. (2012) Sustaining older people's activities during a recession: employability, volunteering and flexible lifestyles. Lessons from academia in an age of austerity. *Geoforum*.
- Department of Health (2013) 2010-2015 Government policy paper: Dementia. Available at: <https://www.gov.uk/government/publications/2010-to-2015-government-policy-dementia> accessed on 3rd October 2015.
- Edwards, R, Reich, M. and Gordon, D. (1975) *Labor Market Segmentation*, Lexington, Mass: DC Heath.
- Elias, M. F., Beiser, A., Wolf, P. A., Au, R., White, R. F., and D'Agostino, R. B. (2000) The preclinical phase of Alzheimer disease: A 22-year prospective study of the Framingham cohort. *Archives of Neurology*. 57 (6), pp.808-813.
- Equality Act (2010) (c15). Available: [http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf) [Accessed 16/4/14: 11:32]
- Edvardsson, D., Fetherstonhaugh, D. and Nay, R. (2010) Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing*, 19, 2611–2618
- Fortuijn, J. D., van der Meer, M., Burholt, V., Ferring, D., Quattrini, S., Hallberg, I. R., Weber, G. and Wenger, G. C. (2006) The activity patterns of older adults: a cross-sectional study in six European countries, *Population, Space and Place*, 12, pp 353–369.
- Garland, L., Lingler, J., Connor, K., Dew, M. (2009) Diagnostic Labels, Stigma, and Participation in Research Related to Dementia and Mild Cognitive Impairment. *Research in Gerontological Nursing*, 2 (2), pp 112-121.
- Goffman, E. (1963) *Stigma: Notes on the management of spoiled identity*. Penguin Books: London

- Grand, J.H.G., Caspar, S., & MacDonald, S.W.S. (2011). Clinical features and multidisciplinary approaches to dementia care. *Journal of Multidisciplinary Healthcare*, 4, pp.125-147.
- Haroutunian, V., Hoffman, L.B., Beerli, M.S. (2009) Is there a neuropathology difference between mild cognitive impairment and dementia? *Dialogues of Clinical Neuroscience*. 11 (2), pp171-9.
- Harris, P. B., and Keady, J. (2009) Selfhood in younger onset dementia: transitions and testimonies. *Aging & Mental Health*. 13(3), pp.437-444.
- Hawton, A., Green, C., Dickens, A., Richards, S. Taylor, R., Edwards, R., Greaves, C. and Campbell, J. (2011) The impact of social isolation on the health status and health-related quality of life of older people, *Qual Life Res*, 20, pp 57–67.
- Hayo.H. (2015) Diagnosis and support for younger people with dementia. *Nursing Standard*, 29 (47), 36-40.
- Hellström, I., Nolan, M., Lundh, U., (2005) 'We do things together': A case study of 'couplehood' in dementia. *Dementia: The International Journal of Social Research and Practice*, 4(1), pp 7-22.
- Hudson, K. (2007) The new labor market segmentation: Labor market dualism in the new economy, *Social Science Research*, 36 (1), pp 286–312.
- Johannessen, A. and Moller, A. (2011) Experiences of persons with early onset dementia in everyday life: A qualitative study. *Dementia*, 12(4), 410-424.
- Kerr, C. (1975) *Labor Markets and Wage Determination: The Balkanization of Labor Markets and Other Essays*, Berkeley: University of California Press.
- Kinney, J. M., Kart, C. S., & Reddecliff, L. (2011). That's me the Goother: Evaluation of a program for individuals with early-onset dementia. *Dementia*, 10(3), 361–377
- Leon, J. (1985) The effects of labor market segmentation on economic resources in retirement, *Social Science Research*, 14 (4), pp 351–373.
- Lindsay, C., McQuaid, R. and Dutton, M. (2007) New approaches to employability in the UK: combining 'human capital development' and 'work first' strategies? *Journal of Social Policy*, 36 (4). pp. 539-560.
- Loretto, W. and White, P. (2006) Population ageing and older workers: employers' perceptions, attitudes and policies, *Population, Space and Place*, 12, pp 341–352. doi: 10.1002/psp.421
- Martin, N. (2009) Reading the signs: while most dementia cases occur among the older population it can also be found in much younger people. *World of Irish Nursing & Midwifery*. 17(9), pp.28-29.
- Mason, J. (2008) Uncovering dementia. *Occupational Health*. 60(10), pp.37-39.
- McCormack B (2004) Person-centredness in gerontological nursing: an overview of the literature. 13, pp 31–38.

McGurk, S. R., and Mueser, K. I. T. (2006) Strategies for coping with cognitive impairments of clients in supported employment. *Psychiatric Services*. 57(10), pp.1421-1429.

Mendez, M.F.(2006) The accurate diagnosis of early onset dementia. *International Journal of Psychiatry in Medicine*. 36(4), 401-412.

Ohman, A., Nygard, L., and Borell, L. (2001) The vocational situation in cases of memory deficits or younger-onset dementia. *Scandinavian Journal of Caring Sciences*. 15(1), pp.34-43.

Office of National Statistics (2011) The labour market and retirement, in Pension Trends. [www.ons.gov.uk/...labourmarket---retirement/chapter-4--labour-ma..](http://www.ons.gov.uk/...labourmarket---retirement/chapter-4--labour-ma..)

Phillipson, C., Bernard, M., Phillips, J. and Ogg, J. (1999) Older people's experiences of community life: patterns of neighbouring in three urban areas, *Sociological Review*, 47, pp 715–743.

Piore, M. and Doeringer, P. (1971) *Internal Labor Markets and Manpower Adjustmen*, New York: D.C. Heath and Company.

Pipon-Young, F. E., Lee, K. M., Jones, F., and Guss, R. (2012) I'm not all gone, I can still speak: The experiences of younger people with Dementia. An action research study. *Dementia*. 11(5), pp.597-616.

Robertson, J., Evans, D. and Horsnell, T. (2013) Side by Side: A workplace engagement program for people with younger onset dementia. *Dementia*, 12(5), 666-674.

Robson, C. (1993) *Real World Research*. Oxford: Blackwell.

Ross, M. and Buehler, R (2004) Identity through time: Constructing personal pasts and futures. In Brewer, M.B. and Hewstone, M. (eds) *Self and Social Identity*. Oxford: Blackwell

Scottish Government (2013) Scotland's National Dementia Strategy 2013-2016. Available at <http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316> accessed on 3rd October 2015.

Starke, S., and Strohschneider, S., (2010), Case Study Research in Psychology. in A. J. Mills, G. Durepos, and E. Wiebe (eds) *Encyclopedia of Case Study Research*, pp 114-117.

Steeman, E., and Tournoy, J. (2013) Managing identity in early-stage dementia: maintaining a sense of being valued *Ageing & Society*, 33, 216 - 242

Taylor, P. and Walker, A. (1994) The ageing workforce – employers' attitudes towards older people, *Work, Employment and Society*, 8(4), pp 569-91.

UN (2000) Replacement Migration: Is It a Solution to Declining and Ageing Populations? New York, United Nations.

Waddell, G., Burton, A. K., and Kendall, N. A.S. (2008) Vocational rehabilitation – what works, for whom, and when? (Report for the Vocational Rehabilitation Task Group). TSO, London. ISBN 9780117038615

- Walker, A. (2006) Active ageing in employment: its meaning and potential, *Asia-Pacific Review*, 13 (1), pp 78-93.
- Walshe, C. (2011) The evaluation of complex interventions in palliative care: An Exploration of the potential of case study research strategies. *Palliative Medicine*. 25 (8), pp 774-781.
- Warr, P., Butcher, V., Robertson, I., and Callinan, M. (2004) Older people's well-being as a function of employment, retirement, environmental characteristics and role preference. *British Journal of Psychology*. 95 (3), pp.297-324.
- Wheelock, J. and Jones, K. (2002) 'Grandparents are the Next Best Thing': informal childcare for working parents in urban Britain, *Journal of Social Policy*, 31, pp 441–463.
- Whittemore, R., and Knafl, K. (2005) The integrative review: updated methodology. *Journal of Advanced Nursing*. 52 (5), pp.546-553.
- Williams, C. (2003) Developing community involvement: contrasting local and regional participatory cultures in Britain and their implications for policy, *Regional Studies*, 37, pp 531–542.
- Yin, R. K. (2009) *Case Study Research: Design and Methods*. California, USA: Sage.



## **13. Appendices**

### List of appendices

13.1 Reference group invite

13.2 Literature review paper, published in the Journal of Public Mental Health

13.3 Key informant invite and consent form

13.4 Ethical approvals for the project and recruitment amendment

13.5 Information sheets and consent forms for case studies

13.6 Identification of other case study participants

13.7 Case study descriptors

## 13.1 Reference group invitation

**Chief Investigator:**

Professor Debbie Tolson  
Alzheimer Scotland Centre  
for Policy and Practice  
UWS  
Hamilton ML3 0JB  
T: 01698283100 ext 8669  
E: debbie.tolson@uws.ac.uk

**Research Team:**

Professor Mike Danson  
Prof of Enterprise Policy  
School of Management  
and Languages  
Heriot-Watt University  
Edinburgh  
EH14 4AS  
T: 0131 451 3840  
E: m.danson@hw.ac.uk

Dr Louise Ritchie  
Research Fellow  
Alzheimer Scotland Centre  
for Policy and Practice  
UWS  
Hamilton ML3 0JB  
T: 01698 283100  
E: louise.ritchie@uws.ac.uk



## DEMENTIA IN THE WORKPLACE: THE POTENTIAL FOR CONTINUED EMPLOYMENT POST-DIAGNOSIS

In line with other European countries the population in the UK is ageing. While increased life expectancy is to be welcomed, older age encompasses a range of challenges including increased prevalence of long term conditions, one of which is dementia. Recent figures suggest that approximately 800,000 people in the UK have dementia; this figure is expected to double within 20 years. While age is one of the main risk factors for dementia, it also affects other age groups; current figures indicate that there are 17,000 younger people with dementia in the UK. Recent changes affecting the state pension age and the abolition of the default retirement age will result in more people with long term conditions being economically active. Because dementia is typically associated with older age, limited attention has been paid to the potential for employment, and little is known about the experiences of people with dementia who are, or would like to be working, or the experiences of employers and co-workers who may provide support.

**Aim:** To explore the employment related experiences of people with dementia or mild cognitive impairment (MCI), and attitudes of employers and/or co-workers towards supporting people with dementia, in order to identify the potential for continued employment post diagnosis

**Specific objectives**

To find out:

- ◆ How people with dementia or MCI cope in the workplace
- ◆ How employers manage challenges associated with employees who show signs of dementia/MCI
- ◆ The level of support that people with dementia or MCI require to retain employment, and whether employers and/or co-workers are able or willing to provide support of this nature

**Methods:** The study adopted a qualitative approach using case studies (n=17). Each case study is based around an individual aged 50-66 who had a diagnosis of dementia or MCI and is in paid employment, or had left within the previous 18 months. Other case study participants include family members, key informants from current or previous workplaces, and relevant service providers. In order to inform the case studies a literature review and one to one interviews (n=18) with a range of key informants was carried out.

**Outcomes:** Analysis focuses on the ways in which people with dementia endeavour to cope in the workplace, the challenges faced by employers and co-workers when an employee displays symptoms of dementia, and ways in which they respond to these challenges. Attention will focus on the level of support or adjustments that people with dementia or MCI would require to extend their working lives, and factors that would enable or hinder employers from providing such support. It will also highlight support needs for people leaving employment, including support with benefits and the process of early retirement.

**(Reference group meeting)**

**UWS HEADED PAPER**

*From: Dr Louise Ritchie  
Institute of Older Persons' Health and Wellbeing  
University of the West of Scotland  
Hamilton. ML3 0JB  
Tel: 01698 283100  
Fax: 01698 300236  
Email: [louise.ritchie@uws.ac.uk](mailto:louise.ritchie@uws.ac.uk)*

Date

Address

**Dear**

**Dementia in the workplace: the potential for continued employment post-diagnosis**

As you are aware, the University of the West of Scotland (UWS) has been awarded funding by the Alzheimer's Society to carry out a research project focusing on the experiences of people who develop dementia or mild cognitive impairment while in employment or self-employment. I enclose a copy of the project information sheet for your information.

We are pleased to announce that work on this project has now commenced on the project. Because of your experience of/professional role and knowledge of/<sup>1</sup> people with dementia we would like to invite you to be involved in our reference group for the project. The first reference group meeting will take place on the 24<sup>th</sup> October 2013 at 10.30 am followed by lunch at 12pm. <LOCATION>

Could you please return the tear-off slip by post or email to me to confirm whether you would like to be involved in the reference group and if you can attend the first meeting. In the meantime if you have any queries please do not hesitate to contact me by telephone: 07734824822, or email: [louise.ritchie@uws.ac.uk](mailto:louise.ritchie@uws.ac.uk).

Yours sincerely

Louise Ritchie

---

**Reference Group Attendance Slip**

Name: \_\_\_\_\_

I would/would not\* like to be involved in the reference group for the project.  
I will/will not\* attend the first reference group meeting on the 24<sup>th</sup> October.

If you are attending:

Do you have any dietary requirements? Yes/No\* If yes, please state \_\_\_\_\_

Do you need a parking space? Yes/No\*

---

\*Delete as appropriate

## 13.2 Article – PDF



## Journal of Public Mental Health

Dementia in the workplace: a review

Louise Ritchie Pauline Banks Michael Danson Debbie Tolson Fiona Borrowman

### Article information:

To cite this document:

Louise Ritchie Pauline Banks Michael Danson Debbie Tolson Fiona Borrowman , (2015), "Dementia in the workplace: a review", Journal of Public Mental Health, Vol. 14 Iss 1 pp. 24 - 34

Permanent link to this document:

<http://dx.doi.org/10.1108/JPMH-04-2014-0015>

Downloaded on: 27 April 2015, At: 06:13 (PT)

References: this document contains references to 19 other documents. To copy this document:

[permissions@emeraldinsight.com](mailto:permissions@emeraldinsight.com)

The fulltext of this document has been downloaded 13 times since 2015\*

### Users who downloaded this article also downloaded:

Elizabeth Breeze, Nicola Jean Hart, Dag Aarsland, Catherine Moody, Carol Brayne, (2015), "Harnessing the power of cohort studies for dementia research", Journal of Public Mental Health, Vol. 14 Iss 1 pp. 8-17 <http://dx.doi.org/10.1108/JPMH-05-2014-0019>

Access to this document was granted through an Emerald subscription provided by

Token:JournalAuthor:4D7AD2EB-03F0-4298-B21A-D26988E224E5:

### For Authors

If you would like to write for this, or any other Emerald publication, then please use our Emerald for Authors service information about how to choose which publication to write for and submission guidelines are available for all. Please visit [www.emeraldinsight.com/authors](http://www.emeraldinsight.com/authors) for more information.

### About Emerald [www.emeraldinsight.com](http://www.emeraldinsight.com)

Emerald is a global publisher linking research and practice to the benefit of society. The company manages a portfolio of more than 290 journals and over 2,350 books and book series volumes, as well as providing an extensive range of online products and additional customer resources and services.

Emerald is both COUNTER 4 and TRANSFER compliant. The organization is a partner of the Committee on Publication Ethics (COPE) and also works with Portico and the LOCKSS initiative for digital archive preservation.

\*Related content and download information correct at time of download.

# Dementia in the workplace: a review

Louise Ritchie, Pauline Banks, Michael Danson, Debbie Tolson and Fiona Borrowman

Dr Louise Ritchie is Research Fellow and Professor

Pauline Banks is Former Director, both at the Institute of Older Persons' Health and Wellbeing, School of Health, Nursing and Midwifery, University of the West of Scotland, Hamilton, UK.

Michael Danson is Professor of Enterprise Policy at School of Management and Languages, Heriot-Watt University, Edinburgh, UK.

Professor Debbie Tolson is Director Alzheimer Scotland Centre for Policy and Practice at School of Health, Nursing and Midwifery, University of the West of Scotland, Hamilton, UK.

Fiona Borrowman is Health Improvement Programme Manager at Health Improvement Programme, Mental Health and Wellbeing in Later Life and Dementia, NHS Health Scotland, Edinburgh, UK.

Received 30 April 2014  
Revised 12 August 2014  
Accepted 9 November 2014

The literature review was funded by an Alzheimer's Society Research Grant No. 180 (PG-2012-199). The project is supported by the Scottish Dementia Clinical Research Network. The interviews were carried out on behalf of NHS Health Scotland and Alzheimer Scotland. The authors are grateful to the interviewees for their permission to publish extracts from the interviews.

## Abstract

**Purpose** – Recent changes affecting state pension age, and earlier diagnosis, will result in more people with dementia in employment. The purpose of this paper is to establish the nature of support that would enable/ enables people with dementia or mild cognitive impairment to continue employment post diagnosis. **Design/methodology/approach** – An integrative review was carried out supported by information derived from a thematic analysis of data from interviews with seven relatives supporting a younger person with dementia and one person with dementia. **Findings** – Six papers were identified for inclusion in the review. Findings from the published papers and interviews indicated that work is a significant issue for people with dementia highlighting problems with job retention, work performance and the impact of diagnosis.

**Research limitations/implications** – The review highlighted a dearth of high-quality research in the area.

Although employment was not the main focus of the interviews, the extracts highlight some of the challenges that face people who develop dementia while of working age, their families, and employers.

**Practical implications** – Vocational rehabilitation is primarily carried out by allied health professionals; however, there is a lack of research evidence relating to people with dementia in the workplace. Further research is needed in order to inform future practice.

**Social implications** – Loss of employment deprives families of financial security and employers of a skilled employee.

**Originality/value** – This is the first review to focus on dementia in employment, providing a starting point on which to base future research in this area.

**Keywords** Employment, Dementia, Alzheimer's disease, Mild cognitive impairment, Vocation, Vocational rehabilitation

**Paper type** Literature review

## Introduction

Approximately 800,000 people in the UK have dementia, of these 17,000 are aged under 65 years (Alzheimer's Society, 2014); with the policy emphasis on earlier diagnosis these figures are set to increase (Alzheimer Disease International, 2012). Recent changes affecting the age at which people become eligible for a state pension and the abolition of the default retirement age will result in more people with dementia being economically active. However, because dementia is typically associated with older age, limited attention has been paid to the potential for employment, and little is known about the experiences of people with dementia who are, or would like to be working, and the experiences of employers and co-workers who may provide support or challenge their right to continue working. This paper presents an integrative review of published literature relating to people with dementia and employment. Following this, data from interviews with seven informal carers supporting a relative who developed dementia while in employment, and one person who recounted their own experience of developing dementia while working, will be presented.

## Background

Bentham and La Fontaine (2007), focusing on services for younger people with dementia in the UK, noted that it is not unusual for people with early symptoms to be made redundant or be

dismissed for incompetence. They found that some younger people with dementia wished to remain in employment, and suggested that efforts should be made to persuade employers to support people to retain appropriate employment and/or to recognise dementia as a reason for early retirement so that pension rights and other benefits are not affected. Under UK social security regulations and eligibility criteria, a diagnosis of long-term health problems/disability can be critical in securing welfare support and, if that has not been forthcoming or is delayed, employment can be essential to maintaining an income. However, receiving a diagnosis can take time.

In recent years there has been a growing awareness of the impact of dementia in the workplace. For example a review carried out by Alzheimer's Australia (2007) reported that first symptoms of dementia often became apparent in the workplace, with decisions to leave employment being prompted by employers. A number of articles have highlighted the need for occupational health professionals to be aware of the problems and be proactive in helping people to gain a diagnosis and secure support to retain employment where possible (Chaston, 2010; Mason, 2008; Martin, 2009).

## Aim

The aim of this review is to establish, from a range of perspectives, the nature of support that would enable/enables people with dementia or mild cognitive impairment to retain employment.

## Search strategy

An integrative review strategy was adopted to cover the diverse range of literature which may exist from a range of disciplines, including health, social sciences and business. Integrative reviews are the broadest type of research review method allowing for the simultaneous inclusion of experimental and non-experimental research in order to more fully understand a phenomenon (Whittemore and Knafl, 2005). They may combine data from theoretical as well as empirical literature, address a range of purposes, and have the potential to produce a comprehensive portrayal of complex concepts. An initial key word search was carried out on a range of databases as shown in Figure 1. Results were screened for relevance first by titles, then by abstracts and finally full papers where adequate information was not available from the titles or abstracts. Inclusion and exclusion criteria are shown in Figure 1.

## Results

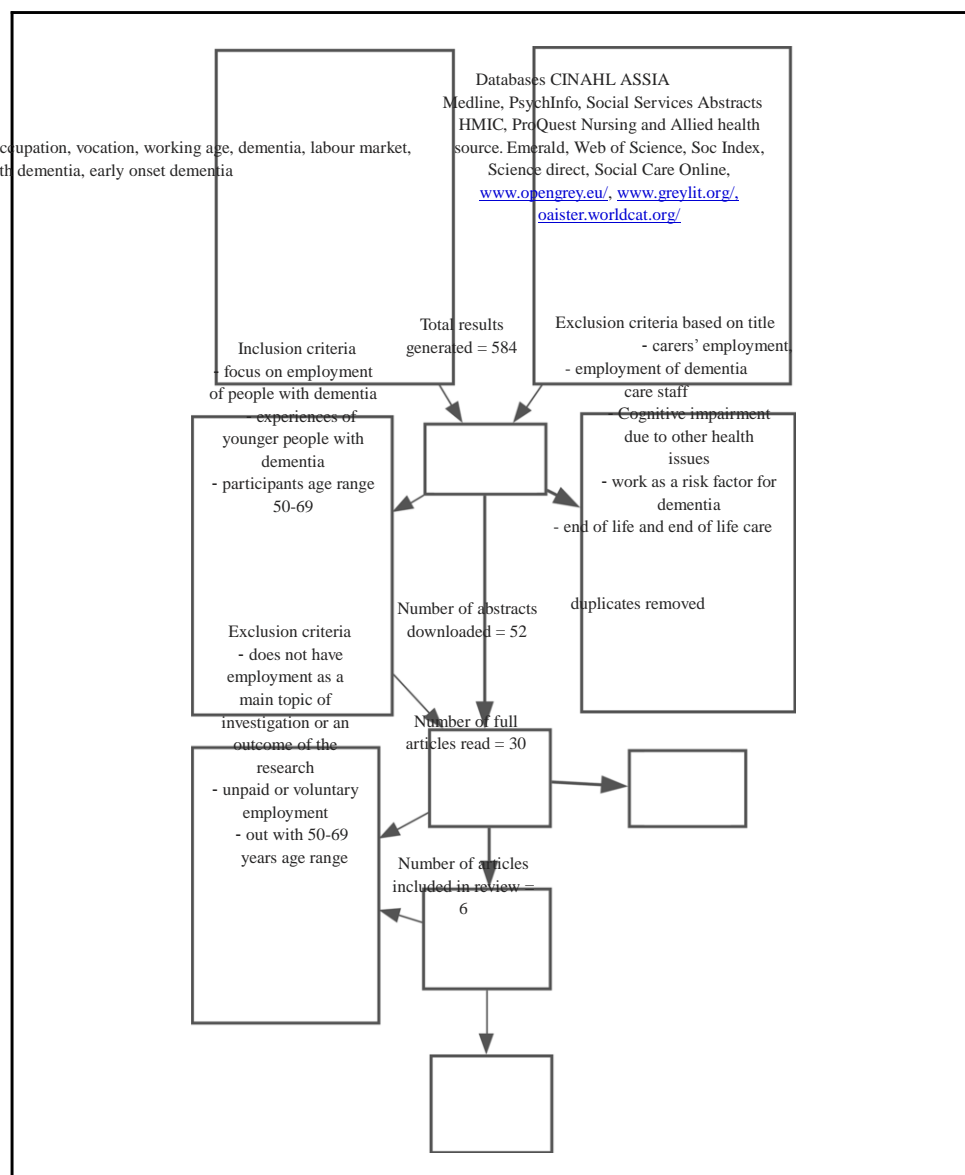
Two papers were identified which directly addressed the experiences of people with dementia in the workplace; three included employment of people with dementia in their outcomes. One paper was identified which examined employers' awareness of dementia in employment. Details of the six papers included in the review are summarised in Table I. Each of these papers was assessed for relevance to the topic and methodological quality. Quality assessment was based on the development of a tool, influenced by the criteria set out by the Joanna Briggs Institute QARI and MASTARI tools[1]. As this review included both qualitative and quantitative research papers, the most appropriate appraisal tool was selected and accordingly a quality score calculated based on the percentage of satisfied criteria. Quality assessments were performed independently by two reviewers and compared to promote rigour. The scores (percentages) are shown in Table I. Due to the small number of papers identified, no paper was excluded on the basis of quality which ranged from 14 per cent (low quality) to 80 per cent (high quality). Following quality rating, information relating to the methodology and outcomes of each paper were extracted and thematically coded. Codes related to the focus of the paper (employer, colleagues or employees), information about the general experience of dementia in the workplace, first symptoms, and supports available and used.

## Experiences of people with dementia in employment: the literature

Four of the six papers identified employment as a concern for people who were diagnosed with dementia at a younger age (<65 years). The exception to this was in research carried out by Pilon-Young et al. (2012). In this study participants reported no issues with employment or retirement as a result of their diagnosis; however, all eight participants were female, in their 60s, and had left work for other reasons prior to diagnosis. In contrast, Harris and Keady (2009)



Keywords Dementia, Alzheimer's disease, MCI, older workers, employment, occupation, vocation, working age, dementia, labour market, younger people with dementia, early onset dementia



categorised “identity as a worker” as their first theme within their research on “Selfhood in Younger Onset Dementia”, which involved interviews with 23 younger people with dementia and 15 family carers. The study found that employment status could be the first thing altered following diagnosis, having a negative impact on the person’s sense of self.

Two papers looked directly at the experiences of people with dementia who had been, or were still, in employment with a diagnosis of dementia or memory problems. Ohman et al. (2001) interviewed nine people about their experiences of dementia or memory problems while still in work. They also interviewed workplace informants for six of the participants. More recently Chaplin and Davidson (2014) interviewed five people about their work-related experiences of dementia. A number of overlapping findings are discussed below.

## Impact of symptoms in the workplace: the literature

Memory failures were the most commonly described initial symptoms in both studies. However, memory problems were not the only symptom and not all participants experienced

**Table I** Papers included in review

Author	Title	Aim	Methodology	Approach	Relevance <sup>a</sup>	Quality <sup>b</sup> (%)
Chaplin and Davidson (2014)	What are the experiences of people with dementia in employment?	To uncover the experiences of people with dementia in employment	Interviews	IPA	High	70
Cox and Pardasani (2013)	Alzheimer's in the workplace: a challenge for social work	To explore the views and experiences of HR professionals relating to dementia	Online questionnaire	Percentages/ grounded theory	High	14
Harris and Keady (2009)	Selfhood in younger onset dementia	To examine the impact a diagnosis has on selfhood and identity	Interviews	Grounded theory/ cross-interview analysis	Medium	60
McGurk and Mueser (2006)	Strategies for coping with cognitive impairments of clients in supported employment	To evaluate the coping strategies used by employment specialists to support clients with cognitive impairments	Questionnaire	Descriptive percentages	Medium	50
Ohman et al. (2001)	The vocational situation in cases of memory deficits or younger onset dementia perceived and met their problems with particular relevance to their present and future vocational situation	To describe how persons with memory deficits or younger onset dementia perceived and met their problems with particular relevance	Interviews	Constant comparative approach	High	80
Pipon-Young et al. (2012)	I'm not all gone, I can still speak: the experiences of younger people with dementia. An action research study	To explore the experiences of younger people with dementia	Interviews/ action research	Thematic analysis	Medium	70

Notes: <sup>a</sup>High relevance: focus of the paper is dementia and employment; medium relevance: focus of the paper is on general experiences of dementia and employment is included as an outcome OR the paper relates to difficulties experienced in the workplace due to cognitive impairment but does not explicitly discuss dementia; low relevance: paper does include employment as a focus or outcome of the research. Low-relevance papers were not included in the review. <sup>b</sup>Methodological quality was assessed using instruments influenced by the Joanna Briggs Institute assessment materials relevant for either qualitative or quantitative-based research. Based on the outcome of each assessment a percentage of the number of criteria met from the applicable criteria was calculated to reflect an overall quality rating for each paper. Due to the low numbers of papers identified as relevant to the review, no papers were excluded on the basis of quality

memory failures. Other problematic symptoms included word-finding, learning new material, using technology, problems with visuo-spatial tasks such as filling in charts, and general issues with concentration and motivation. The participants in Ohman et al.'s study reported that these initial changes in the workplace diminished their confidence in their own ability, and increased stress and anxiety which placed additional pressure on their physical health and abilities. Whereas Chaplin and Davidson highlighted the participants' reluctance to acknowledge the signs of cognitive impairment, passing them off as personality traits or linking them to normal ageing: for example, poorer eyesight. These differing themes may reflect methodological differences rather than different experiences of the participants. However, what is common across both of the papers is that a crisis point was reached where participants realised they could no longer cope in the workplace and had to seek support.

#### Coping strategies in the workplace: the literature

All participants in the Ohman et al. and the Chaplin and Davidson studies reported different strategies that they used to manage/cover up symptoms or to cope with the extra pressures of the workplace. Examples of these are; writing notes and memos, spending more time planning and organising tasks, and making full use of a diary. However, it is unclear how useful these strategies may be, participants in the Ohman et al. study did not find the strategies useful while the participants in Chaplin and Davidson's study found the strategies effective. Similar findings relating to the usefulness of coping strategies were found in a study involving employment specialists supporting people with cognitive impairments in the workplace (McGurk and Mueser, 2006). Totally, 50 employment specialists were then asked to indicate

how often they used each strategy from a list of 76 coping strategies and to rate how useful they thought they were. The employment specialists most often recommended coping strategies for people with problem-solving difficulties, followed by attention and memory problems. However, the strategies which were rated most effective were those which addressed attention problems, while those designed for problem solving were rated least effective. This suggests that, even if coping strategies are not thought to be effective, they are still used.

#### Support in the workplace: the literature

Both the Chaplin and Davidson and the Ohman et al. papers discussed the issues that employers had when informed of an employee's difficulties. It should be noted, though, that in the Chaplin and Davidson study this is only from the perspective of the employee – no employer input was sought. This is reflected by the higher methodological quality score for the Ohman et al. paper. A common finding was that employers appear to lack knowledge to enable them to support people with dementia or cognitive impairment in the workplace. Chaplin and Davidson reported that their employers offered no reasonable adjustments to support their participants to continue employment and that some implemented strategies which led to further confusion and distress for the employee. Employees were likely to be put on sick leave or have their employment terminated, either by being offered early retirement or being dismissed when they received their diagnosis. In the Ohman et al. paper, there was evidence of employers trying to support people to stay in employment; however, adaptations were often ill-informed resulting in further problems. For example, two participants were moved to less challenging jobs within the company. This did not have the desired effect as the employees experienced the same problems with learning new material and processes as they had in their previous roles.

#### Staff perceptions: the literature

The Ohman et al. study benefits from having a workplace perspective as it provides a more balanced view of the situation, including how colleagues felt about supporting colleagues with cognitive impairment. The workplace respondents were positive about wanting to support their colleague to retain employment. However, they noted the difficulties including economic problems related to paying a full salary to someone who was unable to undertake all duties relating to a role, and the negative reaction observed from employees who had to take on additional duties to compensate. It was also interesting to note that while the participants reported having struggled at work for a long period of time, workplace respondents did not report noticing any differences in their colleague until much later.

A recent study carried out by Cox and Pardasani (2013) used an online survey to explore human resources (HR) professionals' awareness relating to dementia in the workplace for both carers of someone with dementia, and employees developing dementia. Totally, 103 HR professionals responded (14.7 per cent). Almost half the respondents (44 per cent) stated they had direct experience of someone developing dementia in the workplace. There were a number of methodological issues with this paper which is highlighted by the low-quality score in Table I. These issues included a potential sample bias and an unclear use of "valid percentages" rather than percentages based on the full sample. Despite these reservations, the study has been included as it was the first study to examine knowledge of employers. It also highlighted the phenomenon of people developing dementia in the workplace although it was unclear how regular an occurrence it was. Where the paper was more useful was in addressing the issues surrounding policy – only 2 per cent of those who answered this question stated that their organisation had a policy in place for dealing with an employee who developed cognitive impairment whilst in work. The online survey included a number of open questions which sought respondents' views and/or concerns about dealing with dementia. Analysis revealed that HR professionals had concerns relating to making inappropriate decisions about the future of a worker; other staff members also experienced increased anxiety and distress when watching a colleague struggling with their work tasks and witnessing their performance decline.

## Experiences of people with dementia in employment: interview data

It is apparent from the above review that there is a dearth of knowledge relating to the experiences of people who develop dementia while in paid employment and ways in which employers could, or should, deal with these people.

In order to develop a resource for younger people with dementia, NHS Health Scotland and Alzheimer Scotland carried out interviews with younger people with dementia and/or their carers. The interviews covered a number of topics including the impact of dementia on employment. In addition to the extracts from the interviews used to develop the online resource, people with dementia and carers who took part in the interviews gave permission for the anonymised transcripts to undergo a secondary analysis by the authors of this paper. The following section presents findings of a thematic analysis (Braun and Clarke, 2006) of the experiences relating to employment, both prior to, and following, diagnosis that were shared during the interviews. The examples presented were derived from eight interviews, seven involving relatives or carers (RC), and one with a person with dementia (PD). Table II provides information relating to the participants including approximate time from identification of difficulties, or seeking help, to diagnosis and nature of dementia where known.

Information derived from the interviews indicates that the length of time from difficulties initially being identified to diagnosis ranged from six weeks to five years. Participants spoke of their experiences of seeking support, the first step towards securing a diagnosis. For a majority of participants, GPs initially focused on stress and depression:

Both of us went [to the GP] together [...] [GP] said it just seemed to be kind of stress, depression. So we came away feeling reassured (RC1).

Participants did not necessarily fare better at memory clinics. RC7 reported that the outcome of the tests did not reflect their day to day reality:

He sailed through [the tests] [...] but, as I said, put him in a car and he was a lethal weapon (RC7).

### Impact of symptoms in the workplace: interview data

Participants spoke of early symptoms; in some instances this involved memory lapses, but in other cases, it was an overall deficit, or change in behaviour:

He was an IT consultant and he couldn't remember his password for his PC. Words were on the tip of his tongue and he couldn't get the words out [...] (RC1).

**Table II** Interview participants, background and time to diagnosis from initially seeking support

Participants	Interviewee	Background	Time to diagnosis
PD1/RC1 consultant	RC1	RC1 supported her husband, PD1, who was diagnosed with dementia in his early 50s. PD1 worked as an IT	5 years
PD2/RC2	RC2	RC2 supported her husband PD2. PD2 was in his late 50s when his dementia caused significant problems. PD2 and PD3 ran a small business together	2 years
PD3/RC3	RC3	RC3 supported her husband PD3, who was diagnosed with frontotemporal dementia in his early 50s. Prior to developing dementia RC3 worked as a free-lance artist	2.5 years
PD4/RC4	PD4	PD4 was living alone at the time of the interview. She was diagnosed with vascular dementia in her 50s. PD4 managed a number of betting shops	6 weeks
PD5/RC5	RC5	RC5 supported his wife PD5, who was diagnosed with dementia in her early 60s. Prior to developing dementia PD5 was an artist and school teacher	6 months
PD6/RC6	RC6	RC6 supported his mother who was diagnosed with vascular dementia and Alzheimer's disease in her late 50s. Prior to her diagnosis RC6 worked for a large airline	18 months
PD7/RC7	RC7	RC7 supported her husband who was diagnosed with Alzheimer's disease in his 50s. He was school teacher	4 years
PD8/RC8	RC8	RC8 supported his mother who was diagnosed with dementia in her mid-50s. PD8 had previously worked as a home carer	1 year

Participants spoke of the inconsistency of symptoms:

You would come in and it would be as if she was alright one minute, and you came back later on that night to see her and you could see a huge difference [...] (RC6).

[He] could still do a crossword, he could still do the Herald crossword [...] on one level he was, his brain wasn't functioning and on the other level it was really good (RC7).

The nature of problems at work, and the impact on individuals and their performance, varied depending on their role. PD4, who managed a number of betting shops, explained that she was not coping at work:

I was dealing with a lot of money and you know, I was leaving money in places that I shouldn't have been [...] (PD4).

RC5 reported that his wife began to find her work increasingly difficult:

The whole process of teaching, of working with pupils, of doing the paperwork which was required became really quite onerous for her (RC5).

RC2, who ran a small business with her husband, found her husband's behaviour very difficult to handle:

We had our own small business [...] he was doing work for people but he went and bought the materials, did the job but came home and he hadn't taken a note of what he'd used, where he did it [...] I couldn't bill anything (RC2).

RC6, who supported his mother, explained that his mother's difficulties were highlighted when she was asked to update her training, which proved to be a problem:

She went to do a job that she had done for twenty years, but she had to redo the training and she couldn't do it (RC6).

For some people previous interest in their work seemed to diminish:

I felt as if I had started slowing down in a lot of things, like being forgetful and, things weren't as important that should have been important [...] (PD4).

Many of the difficulties reported in this section corresponded with those identified in the Ohman et al., and Chaplin and Davidson studies, for example the inconsistency of initial symptoms, both in the nature and consistency from one time period to another, the lack of insight or unwillingness to acknowledge problems, as well as loss of confidence and increased anxiety.

#### Seeking alternative employment: interview data

A number of participants reported that they, or the person with dementia, had tried to make changes in order to remain in paid employment. RC1 explained that when PD1 was initially referred to a neurologist it was suggested that he was experiencing work-related stress:

PD1 was checked out by a neurologist, said, Oh, that's stress, that's depression, dissatisfaction with your job (RC1).

In response to this diagnosis PD1 and his wife decided to become foster carers with PD1 being the main carer while RC1 remained in her current job. However, as soon as he received a diagnosis they resigned.

PD3, who had not been working due to another health issue when his symptoms became apparent, was unable to secure alternative employment:

He was desperately trying to do something, but obviously with him trying new stuff it wasn't working [...] he always wanted to keep working [...] (RC3).

#### Support in the workplace: interview data

RC7 explained that a specific event drew attention to the difficulties PD7, who was a teacher, had been experiencing at work:

Things really did come to a head in his work when I got a phone call from school [...] he hadn't turned up for a class (RC7).

The above incident cited triggered a process within the school in an attempt to manage the situation. However, RC7 did not believe that there was any understanding of the nature of the problem. Following a meeting with his head teacher PD7 was referred to a psychiatrist with a view to devising strategies to enable him to manage his work:

The [proposed] solution at that particular time was that [...] PD7 should go to a computer first thing in the morning and check out what his timetable was for that day [...] the problem was that he would forget to go onto the computer [...] So the solution was just not one, not a solution at all. It was not helpful (RC7).

RC7 explained how difficult it had been:

PD7 was not wanting to go into school [...] to eventually leave under such a cloud was pretty shattering for him, and us (RC7).

Support was also provided by colleagues, for example RC6, who cared for his mother, reported that he had subsequently discovered that she had been experiencing difficulty for some time:

Speaking to her colleagues and friends [...] they had said that they had noticed a change in my Mum [...] they were covering for her, they were kind of trying to help her out (RC6).

Again these findings correspond to the literature reviewed which found that in some instances employers and work colleagues provided support, but where support was offered by employers it was not always successful (Ohman et al., 2001; Chaplin and Davidson, 2014).

#### Leaving the workplace: interview data

For a majority of participants continued work was not an option, some participants had stopped working prior to receiving a diagnosis, either taking early retirement on the basis of ill health or opting for redundancy where available:

[My wife] and I, together, had come to the conclusion that she shouldn't work anymore [...] the final diagnosis came about six months later (RC5).

PD4 explained how the difficulties that she had been experiencing at work became too much, prompting her to leave:

I couldn't cope with it [...] the thought of thousands of money and I was dealing with it [...] I was terrified that I would give somebody a million pounds, just hand it over [...] So I just gave my notice in (PD4).

Again there are similarities with Ohman et al.'s study in which some participants were aware that they were not coping, and in some cases had not been at work for a period of time prior to officially leaving/retiring.

#### Financial impact: interview data

Participants spoke of the financial impact of developing a disability that prohibits continued employment:

You've gone from two high salaries to one salary – that was quite devastating [...] (RC1).

For PD2 and RC2 the loss of their business caused significant financial difficulties:

We were still working, planned to carry on working for as many years. So, like everyone before retirement age there are responsibilities, finances, mortgage, the business [...] (RC2).

RC2 explained how important it was to them to have a clear diagnosis:

Our house was under a repossession order [...] you can imagine that wasn't a pleasant time, but there's no [...] there is no definitive, written diagnosis [...] (RC2).

RC6 gave up his job to care for his mother, with associated financial and social implications. Other carers drew attention to their concerns should they have to stop work in the future in order to provide care, or move house for financial reasons:

If I stop working then yeah, we can't have the house so we're going to have to sell the house and move – that's a huge thing for somebody with dementia [...] (CR3).

While some participants had worked in professional jobs and were able to access a pension on leaving work, they were also at an age where mortgages may not yet be paid off, and children have not yet completed their education:

Obviously it was less money than we had anticipated [...] we also had two girls who were going through many years of education and needed support [...] (RC7).

#### Challenges for employers: interview data

It was apparent that managing people with symptoms of dementia in the workplace was challenging for employers. RC6 acknowledged that it would have been difficult for the trainer working with his mother to comprehend the situation:

The trainer in her training group didn't understand why [mother] couldn't grasp the concept of the training [she] wouldn't see someone with dementia sitting in front of her, her being so young [...] (RC6).

RC7 also recognised the difficulties for her husband's employer:

Very few people would look at [husband] and think there was anything wrong with him. He's a young man, very physically fit, was turning up, was driving into school and it was very hard to realise that something major was going on with his brain [...] (RC7).

While RC7 believed that her husband's situation had not been managed well, she acknowledged that no-one knew what was causing her husband to behave uncharacteristically:

He was brought in and disciplined [...] we didn't know he had Alzheimer's at that point. We just didn't know what was going on [...] (RC7).

The response of these employers reflects the lack of awareness amongst employers and absence of policies for managing dementia in the workplace identified by Cox and Pardasani (2013).

## Discussion

The review presented above, which searched UK and international databases, identified only six papers focusing on dementia in the workplace, with a 13-year gap between the two papers which directly addressed the experiences of people with dementia in employment. The majority of papers were based on qualitative research; the two papers which had a quantitative aspect had methodological failings (Cox and Pardasani, 2013; McGurk and Mueser, 2006).

The inclusion of the qualitative data derived from family carers and one person with dementia illustrated some of the employment-related difficulties experienced by people with dementia, their families, employers and work colleagues. Many of these difficulties corresponded with those identified in the published literature, for example the inconsistency of initial symptoms, loss of confidence and increased anxiety experienced by the person with dementia, ineffectiveness of adjustments provided, and lack of knowledge amongst employers. Only the Ohman et al. (2001) paper included the views of the person with dementia and a workplace representative, other papers focused specifically on the person with dementia (Harris and Keady, 2009; Pipon-Young et al., 2012; Chaplin and Davidson, 2014), HR professionals (Cox and Pardasani, 2013), or other employment specialists (McGurk and Mueser, 2006).

The UK Equality Act (2010) prohibits discrimination against people with disabilities. However, information derived from the review and extracts from the interviews indicate that securing a diagnosis of dementia can take time, and without a diagnosis individuals will be unable to benefit from the provision of the Act. The development of dementia may be preceded by a period of reduced capacity for new learning, retention, abstract reasoning, episodic and/or semantic memory (Grand et al., 2011). This period, in which symptoms may be ambiguous, can be challenging for employees and their employers, particularly when a younger person is involved.

There is currently a lack of evidence relating to the experiences of people who develop dementia while working and as well as the experiences of their employers, co-workers and occupational health professionals who may provide support. Participants in the interviews were all in contact with Alzheimer Scotland and not necessarily a representative sample. Nevertheless, it is critical

that we learn from the experiences of people with dementia and their carers. Issues raised in the interviews but not addressed in the literature include the financial impact on people who develop dementia while of working age, and their families, as well as the economic impact on employers.

Developing dementia while of working age has a devastating impact on those affected and their families. Loss of employment deprives families of financial security and employers of a skilled employee. Vocational rehabilitation is primarily carried out by allied health professionals; however, there is a lack of research evidence relating to people with dementia in the workplace and thus little advice, guidance and good practice support is available to help people with dementia to remain in the labour market, focusing on retaining ability rather than on deficits.

### Implications for the future

Given the focus in the social security system and in welfare reforms of making employment the route out of poverty on the one hand, and the more positive arguments for continued attachment to work to promote well-being and employability on the other (Lindsay et al., 2007), this review highlights the need for further research. Currently employers lack the knowledge and understanding that would enable them to manage the growing number of employees with dementia as the workforce ages. Further research is needed to scope the policies already in place to deal with dementia in the workplace, as well as raising awareness amongst HR and occupational health professionals which is vital to the implementation of such policies.

### Note

1. <http://joannabriggs.org/assets/docs/sumari/ReviewersManual-2011.pdf>

### References

- Alzheimer Disease International (2012), "National alzheimer and dementia plans planned policies and activities: early detection, access to diagnosis, and stigma reduction", Alzheimer Disease International, available at: [www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf](http://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf) (accessed 23 April 2014).
- Alzheimer's Australia (2007), "Exploring the needs of younger people with dementia in Australia", available at: [www.fightdementia.org.au/services/further-reading-and-resources.aspx](http://www.fightdementia.org.au/services/further-reading-and-resources.aspx) (accessed 17 April 2014).
- Alzheimer's Society (2014), "Statistics", available at: [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=14341](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=14341) (accessed 25 February 2014).
- Bentham, P. and La Fontaine, J. (2007), "Service development for younger people with dementia", *Psychiatry*, Vol. 70 No. 2, pp. 84-7.
- Braun, V. and Clarke, V. (2006), "Using thematic analysis in psychology", *Qualitative Research in Psychology*, Vol. 3 No. 2, pp. 77-101.
- Chaplin, R. and Davidson, I. (2014), "What are the experiences of people with dementia in employment?", *Dementia*, doi:10.1177/1471301213519252, first published on 13 January 2014, doi:10.1177/1471301213519252.
- Chaston, D. (2010), "Younger adults with dementia: a strategy to promote awareness and transform perceptions", *Contemporary Nurse: A Journal for the Australian Nursing Profession*, Vol. 34 No. 2, pp. 221-9.
- Cox, C.B. and Pardasani, M. (2013), "Alzheimer's in the workplace: a challenge for social work", *Journal of Gerontological Social Work*, Vol. 56 No. 8, pp. 643-56.
- Equality Act (2010), "c15", available at: [www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf) (accessed 16 April 2014).
- Grand, J.H.G., Caspar, S. and MacDonald, S.W.S. (2011), "Clinical features and multidisciplinary approaches to dementia care", *Journal of Multidisciplinary Healthcare*, Vol. 4 No. 1, pp. 125-47.
- Harris, P.B. and Keady, J. (2009), "Selfhood in younger onset dementia: transitions and testimonies", *Aging & Mental Health*, Vol. 13 No. 3, pp. 437-44.
- Lindsay, C., McQuaid, R. and Dutton, M. (2007), "New approaches to employability in the UK: combining 'human capital development' and 'work first' strategies?", *Journal of Social Policy*, Vol. 36 No. 4, pp. 539-60.



- McGurk, S.R. and Mueser, K.I.T. (2006), "Strategies for coping with cognitive impairments of clients in supported employment", *Psychiatric Services*, Vol. 57 No. 10, pp. 1421-9.
- Martin, N. (2009), "Reading the signs: while most dementia cases occur among the older population it can also be found in much younger people", *World of Irish Nursing & Midwifery*, Vol. 17 No. 9, pp. 28-9.
- Mason, J. (2008), "Uncovering dementia", *Occupational Health*, Vol. 60 No. 10, pp. 37-9.
- Ohman, A., Nygard, L. and Borell, L. (2001), "The vocational situation in cases of memory deficits or younger-onset dementia", *Scandinavian Journal of Caring Sciences*, Vol. 15 No. 1, pp. 34-43.
- Pipon-Young, F.E., Lee, K.M., Jones, F. and Guss, R. (2012), "I'm not all gone, I can still speak: the experiences of younger people with dementia. An action research study", *Dementia*, Vol. 11 No. 5, pp. 597-616.
- Whittemore, R. and Knafl, K. (2005), "The integrative review: updated methodology", *Journal of Advanced Nursing*, Vol. 52 No. 5, pp. 546-53.

## Further reading

Warr, P., Butcher, V., Robertson, I. and Callinan, M. (2004), "Older people's well-being as a function of employment, retirement, environmental characteristics and role preference", *British Journal of Psychology*, Vol. 95 No. 3, pp. 297-324.

## About the authors

Dr Louise Ritchie is a Research Fellow at the University of the West of Scotland. Her research focuses on health and well-being of older people, with particular interest in people with dementia. Dr Louise Ritchie is the corresponding author and can be contacted at: [louise.ritchie@uws.ac.uk](mailto:louise.ritchie@uws.ac.uk)

Pauline Banks is a Professor of Older Persons' Health at the UWS, and the Director of the Institute of Older Persons' Health and Wellbeing. Her research has focused on health, social care, education and employment across all ages.

Michael Danson is a Professor of Enterprise Policy and the Director of Doctoral Programmes, SML at the Heriot-Watt University, Edinburgh. He has written widely on employment and economic development.

Professor Debbie Tolson is the Alzheimer Scotland Professor of Dementia and the Director of the Alzheimer Scotland Centre for Dementia Policy and Practice at the UWS. She is a nurse educator, researcher and author with publications relating to later life, dementia, nursing home practice and family caring. In 2010 she was awarded the distinguished Jim Flood Alzheimer Lectureship from the St Louis Medical School, USA for her applied research.

Fiona Borrowman is presently a Health Improvement Manager for Mental Health and Wellbeing in Later Life and Dementia at the NHS Health Scotland. The NHS Health Scotland Mental Health and Wellbeing in Later Life Programme over the last ten years has developed a health improvement programme of work including: promotion of physical activity, mental health and well-being, falls prevention, osteoporosis awareness and dementia.

---

For instructions on how to order reprints of this article, please visit our website:

[www.emeraldgroupublishing.com/licensing/reprints.htm](http://www.emeraldgroupublishing.com/licensing/reprints.htm)

Or contact us for further details: [permissions@emeraldinsight.com](mailto:permissions@emeraldinsight.com)

### 13.3 Key Informant invitation

*From: Dr Louise Ritchie  
Director Institute of Older Persons' Health and Wellbeing  
University of the West of Scotland  
Hamilton, ML3 0JB  
Tel: 01698 283100  
Fax: 01698 300236  
Email: [louise.ritchie@uws.ac.uk](mailto:louise.ritchie@uws.ac.uk)*

*Date*

*Address*

**Dear**

**Dementia in the workplace: the potential for continued employment post-diagnosis**

As you are aware, the University of the West of Scotland (UWS) has been awarded funding by the Alzheimer's Society to carry out a research project focusing on the experiences of people who develop dementia or mild cognitive impairment while in employment or self-employment.

The aim of the project is to find out whether it is possible for people with dementia or mild cognitive impairment (MCI) to remain in employment after diagnosis. We are interested in the nature and level of support or adjustments that people with dementia or MCI would require to extend their working lives, and factors that would enable or hinder employers from providing such support.

Because of your experience of/professional role and knowledge of<sup>1</sup> people with dementia we would like to invite you to take part in an interview. The interview would be arranged at a time to suit you and may be conducted at a place of your choice or by telephone. Interviews would last for around 15-20 minutes and be carried out by a member of the research team at UWS.

I enclose a copy of the project information sheet for your information and will telephone you within the next week to see if you would be willing to take part in an interview. In the meantime if you have any queries please do not hesitate to contact me by telephone: 01698 283100, or email: [louise.ritchie@uws.ac.uk](mailto:louise.ritchie@uws.ac.uk).

Yours sincerely

Louise Ritchie

---

<sup>1</sup> Delete as appropriate

## 13. 4 Ethical approvals

List of documents reviewed amended (version no and date added of invitation letter) and letter re-issued on 11 July 2013

**WoSRES**

**West of Scotland Research Ethics Service**



**West of Scotland REC 4** Ground Floor, Tennent  
Building Western Infirmary  
38 Church Street Glasgow  
G11 6NT  
[www.nhsqgc.org.uk](http://www.nhsqgc.org.uk)

Professor Pauline Banks Professor Older Persons'  
Health University of the West of Scotland  
Institute of Older Persons' Health and Wellbeing  
Caird Building, Hamilton Campus  
Hamilton ML3 0JB

Date 20 June 2013  
Direct line 0141-211-1722  
Fax 0141-211-1847  
ail evelyn.jackson@ggc.scot.nhs.uk

Dear Professor Banks

<b>Study title:</b>	<b>Dementia in the workplace: a feasibility study exploring the employment related experiences of people with dementia or mild cognitive impairment and their employers or co- workers to identify the potential for continued employment post diagnosis</b>
<b>REC reference:</b>	<b>13/WS/0145</b>
<b>IRAS project ID:</b>	<b>126790</b>

The Research Ethics Committee reviewed the above application at the meeting held on 7 June 2013. The Committee thank you and Professor Mike Danson for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Ms Evelyn Jackson, [evelyn.jackson@ggc.scot.nhs.uk](mailto:evelyn.jackson@ggc.scot.nhs.uk).

Ethical opinion

**Ethical issues raised by the Committee in private discussion, together with responses given by the researcher when invited into the meeting:**

The Committee asked you how the cognitive ability of potential participants with dementia will be assessed.

You explained that you would rely on the person themselves and their family members to assess their cognitive ability to take part in the study.

The Committee asked you if you expected participants to become upset during interview and asked how this would be handled.

You explained that should anyone become upset during their participation in the study they would be offered appropriate help or support.

The Committee noted that one of the peer reviewers had concerns regarding how open colleagues may feel that they can be about the person with dementia and may feel that they had not been as supportive as they might have been and asked you about your thoughts on this.

You informed the Committee that you were aware of this potential aspect of participating in the study and felt that this would be a very important and informative aspect of the study. You also stated that should a participant become upset during the interview that they would be offered help and support.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

In the Participant Information Sheet 1:

There is no clear explanation of what someone who wishes to take part in the study after they have read the Information Sheet, should do to take this forward.

In the section headed “What would taking part in the study involve?”, 2<sup>nd</sup> paragraph, should be changed by moving the second sentence to the beginning and in the second sentence add that the researcher will speak to the work colleagues and managers identified by the participant.

Although it had been acknowledged that participants with dementia could become tired, it is considered that the topics to be discussed would not be embarrassing or upsetting as answered in QA23 of the IRAS application form. This Committee asked that this be explained.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to

facilitate their permission for the study. Failure to provide the final

**versions to the REC may cause delay in obtaining permissions.**

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission (“R&D approval”) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites (“participant identification centre”), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

## **Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter	-	17 May 2013
REC application		20 May 2013
Protocol	2	14 May 2013
Summary/Synopsis	1	20 March 2013
Investigator CV	-	20 March 2013
Letter of invitation to participant	2	23 April 2013
Interview Schedules/Topic Guides	1	14 March 2013
Evidence of insurance or indemnity	-	12 July 2012
Participant Information Sheet: PIS1	2	20 May 2013
Participant Information Sheet: PIS2	1	20 May 2013
Participant Information Sheet: Workplace PIS	2	25 April 2013
Participant Information Sheet: Case Study PIS	2	23 April 2013
Participant Information Sheet: Relative or Carer Information Sheet	2	23 April 2013
Participant Consent Form: Person with Dementia or Mild Cognitive Impairment	1	20 May 2013
Participant Consent Form: Workplace	2	25 April 2013
Participant Consent Form: Case Study	2	23 April 2013
Participant Consent Form: Relative or Carer	2	23 April 2013



Letter from Sponsor	-	17 May 2013
Other: Letter from funder	-	19 February 2013
Other: Visual timeline	-	-
Other: Relative/carer interview schedule	1	08 March 2013
Other: Workplace colleague interview schedule	1	14 March 2013
Other: Workplace Participant Interview schedule(Manager et al)	2	14 May 2013
Other: Case study Participant Interview schedule	1	14 March 2013
Other: Identification of case study participants sheet	2	20 May 2013
Other: Project information sheet	1	14 May 2013
Other: Response to reviewers' comments	-	11 January 2013
Referees or other scientific critique report	-	-

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

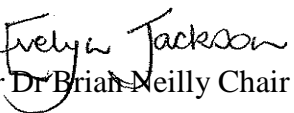
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/WS/0145 Please quote this number on all correspondence
---

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project. Yours sincerely

  
For Dr Brian Neilly Chair

*Enclosures: List of names and professions of members who were present at the meeting "After ethical review – guidance for researchers"*

*Copy to: Dr Heather Simpson  
Mr Raymond Hamill, R&D Department, NHS Lanarkshire*

**Attendance at Committee meeting on 07 June 2013 Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr Gavin Bell	Lay Member	Yes	
Ms Lynda Brown	Public Health Adviser	Yes	
Mr Thomas Byrne	Lay Member	Yes	
Dr Clair Evans	Consultant Paediatric and Perinatal Pathologist	No	
Dr Claire Fang	GP	Yes	
Dr Ken James	Consultant Anaesthetist	Yes	
Dr Grace Lindsay	Reader	Yes	
Miss Fiona Mackelvie	Retired (Lay plus member)	Yes	
Dr Brian Neilly	Consultant Physician	Yes	
Dr Linda Renfrew	Consultant Physiotherapist in MS	Yes	
Dr Jackie Riley	Statistician	Yes	
Dr Giles Roditi	Consultant Radiologist	Yes	
Dr Ihab Shaheen	Consultant Paediatric Nephrologist	Yes	
Dr Gary Tanner	Consultant Psychologist	No	
Mrs Kathleen Tuck	Retired Teacher (Lay plus member)	No	
Mr Iain Wright	Consultant Engineer (Lay plus member)	No	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr Judith Godden	Scientific Adviser
Ms Evelyn Jackson	Committee Co-ordinator

List of documents reviewed amended (version no and date of invitation letter added) and letter re-issued on 11 July 2013

**WoSRES**  
**West of Scotland Research Ethics Service**



Professor Pauline Banks Professor  
Older Persons' Health University of the  
West of Scotland  
Institute of Older Persons' Health and  
Wellbeing  
Caird Building Hamilton Campus  
Hamilton  
ML3 0JB e-mail [evelyn.jackson@ggc.scot.nhs.uk](mailto:evelyn.jackson@ggc.scot.nhs.uk)

**West of Scotland REC 4** Ground Floor, Tennent  
Building Western Infirmary  
38 Church Street Glasgow  
G11 6NT  
[www.nhsggc.org.uk](http://www.nhsggc.org.uk)

Date 26 June 2013  
Direct line 0141-211-1722  
Fax 0141-211-1847

Dear Professor Banks

<b>Study title:</b>	<b>Dementia in the workplace: a feasibility study exploring the employment related experiences of people with dementia or mild cognitive impairment and their employers or co-workers to identify the potential for continued employment post diagnosis</b>
<b>REC reference:</b>	<b>13/WS/0145</b>
<b>IRAS project ID:</b>	<b>126790</b>

Thank you for your letter of 24 June 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 20 June 2013

Documents received

The documents received were as follows:

<b>Document</b>	<b>Version</b>	<b>Date</b>
Other: Covering letter	-	24 June 2013
Participant Information Sheet: PIS 1 - Person with dementia or mild cognitive impairment	3	21 June 2013

## Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering Letter	-	17 May 2013
Protocol	2	14 May 2013
REC application	-	20 May 2013
Summary/Synopsis	1	20 March 2013
Investigator CV	-	20 March 2013
Letter of invitation to participant	2	23 April 2013
Participant Information Sheet: PIS 1 - Person with dementia or mild cognitive impairment	3	21 June 2013
Participant Information Sheet: PIS2	1	20 May 2013
Participant Information Sheet: Workplace PIS	2	25 April 2013
Participant Information Sheet: Case Study PIS	2	23 April 2013
Participant Information Sheet: Relative or Carer Information	2	23 April 2013
Participant Consent Form: Person with Dementia or Mild Cognitive Impairment	1	20 May 2013
Participant Consent Form: Workplace	2	25 April 2013
Participant Consent Form: Case Study	2	23 April 2013
Participant Consent Form: Relative or Carer	2	23 April 2013
Interview Schedules/Topic Guides	1	14 March 2013
Evidence of insurance or indemnity	-	12 July 2012
Letter from Sponsor	-	17 May 2013
Other: Letter from funder	-	19 February 2013
Other: Visual timeline	-	-
Other: Relative/carers interview schedule	1	08 March 2013
Other: Workplace colleague interview schedule	1	14 March 2013
Other: Workplace Participant Interview schedule(Manager et	2	14 May 2013
Other: Case study Participant Interview schedule	1	14 March 2013
Other: Identification of case study participants sheet	2	20 May 2013
Other: Project information sheet	1	14 May 2013
Other: Response to reviewers' comments	-	11 January 2013
Other: Covering letter	-	24 June 2013
Referees or other scientific critique report	-	-

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

Yours sincerely

A handwritten signature in black ink that reads "Evelyn Jackson". The signature is written in a cursive style with a large, stylized 'E' and 'J'.

Ms Evelyn Jackson Committee Co-ordinator

*Copy to: Dr Heather Simpson,  
Mr Raymond Hamill, R&D Department, NHS Lanarkshire*

Professor Pauline Banks Professor Older  
Persons' Health University of the West of  
Scotland  
Institute of Older Persons' Health and  
Wellbeing Caird Building, Hamilton Campus

**West of Scotland REC 4** Ground Floor,  
Tennent Building Western Infirmary  
38 Church Street Glasgow  
G11 6NT  
[www.nhsggc.org.uk](http://www.nhsggc.org.uk)

Date 4 June 2014

Hamilton Direct line  
ML3 0JB

0141-211-1722  
Fax 0141-211-1847  
e-mail [Wosrec4@ggc.scot.nhs.uk](mailto:Wosrec4@ggc.scot.nhs.uk)

Dear Professor Banks

<b>Study title:</b>	<b>Dementia in the workplace: a feasibility study exploring the employment related experiences of people with dementia or mild cognitive impairment and their employers or co-workers to identify the potential for continued employment post diagnosis</b>
<b>REC reference:</b>	<b>13/WS/0145</b>
<b>Amendment number:</b>	<b>AM02</b>
<b>Amendment date:</b>	<b>19 May 2014</b>
<b>IRAS project ID:</b>	<b>126790</b>

The above amendment was reviewed by the Sub-Committee, in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Summary of amendment:

Changes to recruitment in order to facilitate recruitment of participants in England.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Notice of Substantial Amendment (non-CTIMP)	AM02	19 May 2014
Other [Dementia in the workplace - info for web and	1	13 May 2014
Other [Details of amendments]	AM02	-

## Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

## R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>13/WS/0145: Please quote this number on all correspondence</b>
---

Yours sincerely



*For Dr Brian Neilly Chair*

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Mr Raymond Hamill, R&D, NHS Lanarkshi*



## 13.5 Case study consent forms

## **DEMENTIA IN THE WORKPLACE: THE POTENTIAL FOR CONTINUED EMPLOYMENT POST- DIAGNOSIS**

### **Participant Information Sheet 1** *(PERSON WITH DEMENTIA OR MILD COGNITIVE IMPAIRMENT)*

We would like to invite you to take part in a research study. This information sheet provides information about the study and what would be involved if you decide to take part. Before you decide, we would like you to understand why the research is being carried out and what it would involve for you. Take time to think it over, discuss it with family, friends, work colleagues if you are working, and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information, contact details are included at the end of this document, and a member of the research team would be pleased to discuss the study with you.

#### **Who is doing the research?**

The research will be carried out by staff from the University of the West of Scotland who are working with staff from Heriot Watt University, in Edinburgh. The project has the full support of Alzheimer Scotland, the Scottish Dementia Clinical Research Network, and the Alzheimer's Society. The project has been funded by the Alzheimer's Society.

#### **What is the study about?**

We are interested in the experiences of people who develop dementia or mild cognitive impairment while in employment. The aim of the research is to find out whether it is possible for people with dementia or mild cognitive impairment to remain in employment after diagnosis, and if so what support they would need for them to do so.

#### **Why have I been invited to take part in the study?**

You have been invited to take part in this study because you have a diagnosis of dementia or mild cognitive impairment, and are in paid employment, self-employed, or left work less than 18 months ago. We hope to speak to twenty

people who have developed dementia or mild cognitive impairment while still working.

### **What would taking part in the study involve?**

If you are interested in taking part in the study, a member of the research team from the University of the West of Scotland will contact you to tell you more about the project and answer any questions that you may have. If you then decide that you do want to take part in the study you will be invited to take part in an interview. A member of the research team will arrange a time that is suitable to visit you in your home, or another place of your choice, and ask about your experiences at work. Interviews should last approximately one hour. If you would like a relative or friend to be with you during the interview, they are welcome to be present.

If you do decide to take part in the study we would also wish to speak to any family, friends or work colleagues, e.g. manager, or colleagues, who may have supported you to continue working. If you identify people who have supported you, we would like to have your permission to approach them to talk about that support.

### **What are the benefits or disadvantages in taking part?**

There would be no direct benefit to you from taking part in the project. However, we believe this study will help other people with dementia who are working, or would like to be working, by informing support services and employers about the needs and concerns of people with dementia or mild cognitive impairment who are in work, self-employment or have recently left work.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. Participation is entirely voluntary and you would be free to withdraw at any time without giving a reason; withdrawal would have no impact on any support that you are currently receiving. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

### **What will happen to information collected in the study?**

All information collected during the course of the study will be kept strictly confidential. No individual will be identified in the study report or any other publication. We may wish to use some quotations to illustrate specific points. Any information used in this way will be anonymised. Audio recordings will be destroyed once they have been transcribed. All participants will be provided with a copy of the final report.

**What will I do if I am interested in taking part?**

If you are interested in the study, and possibly taking part, please tell the person who gave you this information sheet, or contact either Pauline Banks or Louise Ritchie who will arrange to visit you and answer any questions.

Professor Debbie Tolson  
T: 01698 283100  
E: [Debbie.tolson@uws.ac.uk](mailto:Debbie.tolson@uws.ac.uk)



Louise Ritchie  
Tel: 01698 283100 ext 8690  
Email: [louise.ritchie@uws.ac.uk](mailto:louise.ritchie@uws.ac.uk)

**Further information about this research study:**

Members of the research team will be pleased to answer any question you may have and can be contacted at:

The School of Health, University of the West of Scotland, Hamilton. ML3 0JB

Contact	Telephone	Email
Professor Debbie Tolson	01698 283100	<a href="mailto:debbie.tolson@uws.ac.uk">debbie.tolson@uws.ac.uk</a>
Professor Mike Danson	0131 451 3840	<a href="mailto:M.Danson@hw.ac.uk">M.Danson@hw.ac.uk</a>
Dr Louise Ritchie	01698 283100	<a href="mailto:louise.ritchie@uws.ac.uk">louise.ritchie@uws.ac.uk</a>

**Thank you for reading this information sheet.**

**DEMENTIA IN THE WORKPLACE:  
THE POTENTIAL FOR CONTINUED EMPLOYMENT POST-  
DIAGNOSIS**

**Participant Consent Form**  
(PERSON WITH DEMENTIA OR MILD COGNITIVE IMPAIRMENT)

Participant ID:.....

Date:.....

Principal Researcher: Prof Debbie Tolson

Please initial

I confirm that I have read and understand the information sheet dated 21 <sup>st</sup> June, 2013 (version 3) for the above research study.	
I have had the opportunity to think about the information, ask questions, and have them answered satisfactorily.	
I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason.	
I am happy for interview to be recorded and transcribed, and for word for word quotations to be used in reports with the understanding that they will be anonymised.	
I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

When completed, 1 for participant: 1 researcher site file (original)

## **DEMENTIA IN THE WORKPLACE: THE POTENTIAL FOR CONTINUED EMPLOYMENT POST- DIAGNOSIS**

### **Participant Information Sheet 2** *(PERSON WITH DEMENTIA OR MILD COGNITIVE IMPAIRMENT)*

You have expressed an interest in taking part in a research study, and we would like to thank you for the time that you have taken to meet with a member of the research team to discuss what it would mean to you if you decide to take part.

We hope that we have been able to answer all your questions; however, we know that it is very easy to think of things that you wish you had asked. This information sheet tries to answer some of the things that you might want to know. If there is still information that you would like, please contact a member of the research team, details are included at the end of this document:

#### **Who is doing the research?**

The research will be carried out by staff from the University of the West of Scotland who are working with staff from Heriot Watt University, in Edinburgh.

#### **Who is funding the study?**

The project, which has the full support of Alzheimer Scotland, the Scottish Dementia Clinical Research Network, and the Alzheimer's Society, is being funded by the Alzheimer's Society.

#### **What is the study about?**

We are interested in the experiences of people who develop dementia or mild cognitive impairment while in employment. We want to find out whether it is possible for people with dementia or mild cognitive impairment to remain in employment after diagnosis, and if so what support they would need for them to do so.

#### **How will the study be carried out?**

We are interested in how people with dementia or mild cognitive impairment manage at work, and what support is available for them. We are interested in

how employers and other people at work support people who develop dementia, as well as the role of health and social care professionals. The study will involve interviews with these people.

### **What would taking part in the study involve?**

If you decide to take part in the study you will be invited to take part in an interview. A member of the research team will arrange a time that is suitable to visit you in your home, or another place of your choice, and ask about your experiences at work, and what happened when you first had symptoms of dementia, and the type of support that you received or would have liked to receive. We would like to record interviews and would ask for permission to do so at the time. If you would like a relative or friend to be with you during the interview, they are welcome to be present.

### **How long will the study take?**

Interviews should last approximately one hour. However, if you become tired or there are issues that are not fully explored during your interview, the researcher will ask if it would be possible to meet with you again.

### **Who else will be involved in the study?**

As well as speaking to you about your experiences at work, we would like to speak to members of your family, or friends, who have provided you with support while working, and if possible people from your current or previous workplace e.g. employers, trades union representatives, occupational health professionals.

If you do identify people from your current or previous workplace who might take part in the project, and they are willing to take part in an interview, we would ask them about working with you when you developed symptoms of dementia, for example did they notice that you were having problems, have they worked with anyone else who has developed dementia at work, their general knowledge relating to dementia including personal experience, and their views relating to supporting people with dementia in the workplace.

If you are happy to do this, there is a form on which you can provide contact details for anyone that you are happy for a member of the research team to contact - doing this means that if you identify someone from your workplace, or anyone else that you think might take part in the project, they will know that you have given us permission to speak to them. If you are happy to identify someone, but do not want to identify your workplace, we can provide you with information about the study to send to them directly, and it is then up to them to decide whether or not to contact us.

You do not need to identify other people right away. If you decide to take part, you can discuss it further with the researcher at your interview.

**If someone from my current or previous work takes part, will I know what they say?**

All information collected during the course of the study will be confidential. Nothing that you say, or anyone else says, during an interview will be made available to other participants. However, should a participant say anything that might affect the safety of others, it would be necessary to report this to an appropriate authority, we would discuss this with the participant at the time. No individual will be identified in the study report or any other publication. We may wish to use some word for word quotations to illustrate specific points. Any information used in this way will be anonymised. Audio recordings will be destroyed once they have been transcribed. All participants will be provided with a copy of the final report.

**What are the benefits or disadvantages in taking part?**

It is unlikely that you would benefit directly from taking part in the project. However, we believe this study will help inform other people including support services and employers about the needs and concerns of people with dementia or mild cognitive impairment who are in work, self-employment or have recently left work.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you would be free to withdraw at any time without giving a reason; withdrawal would have no impact on any support that you are currently receiving. Should you be unable to continue for any reason, you could decide whether or not you wish your contribution to date to be included in the study – the person who interviewed you would be happy to discuss your wishes with you.

**If you would like further information or to speak to a member of the research team please contact at:**

The School of Health, University of the West of Scotland, Hamilton. ML3 0JB

Contact	Telephone	Email
Professor Pauline Banks	01698 283100 Ext 8557	<a href="mailto:pauline.banks@uws.ac.uk">pauline.banks@uws.ac.uk</a>
Professor Mike Danson	0131 451 3840	<a href="mailto:M.Danson@hw.ac.uk">M.Danson@hw.ac.uk</a>
Professor Debbie Tolson	01698 283100	<a href="mailto:debbie.tolson@uws.ac.uk">debbie.tolson@uws.ac.uk</a>
Dr Louise Ritchie	01698 283100	<a href="mailto:louise.ritchie@uws.ac.uk">louise.ritchie@uws.ac.uk</a>

**Thank you for reading this information sheet.**



## **DEMENTIA IN THE WORKPLACE: THE POTENTIAL FOR CONTINUED EMPLOYMENT POST- DIAGNOSIS**

### **Workplace Participant Information Sheet**

We would like to invite you to take part in a research study. This information sheet provides information about the study and what would be involved if you decide to take part. Before you decide, we would like you to understand why the research is being carried out and what it would involve for you. Take time to think it over, discuss it with family, friends, or workplace colleagues. Ask us if there is anything that is not clear or if you would like more information, contact details are included at the end of this document, and a member of the research team would be pleased to discuss the project with you.

#### **Who is doing the research?**

The research will be carried out by staff from the University of the West of Scotland who are working with staff from Heriot Watt University, in Edinburgh. The project has the full support of Alzheimer Scotland, the Scottish Dementia Clinical Research Network, and the Alzheimer's Society. The project has been funded by the Alzheimer's Society.

#### **What is the study about?**

We are interested in the experiences of people who develop dementia or mild cognitive impairment while in employment. The aim of the project is to find out whether it is possible for people with dementia or mild cognitive impairment (MCI) to remain in employment after diagnosis. We are interested in the challenges faced by employers and co-workers when an employee displays symptoms of dementia, and ways in which they respond to these challenges, as well as the nature and level of support or adjustments that people with dementia or MCI would require to extend their working lives, and factors that would enable or hinder employers from providing such support.

#### **Why have I been invited to take part in the project?**

You have been invited to take part in this research because .....developed dementia or mild cognitive impairment while working with you and has given

us permission to contact you and invite you to take part in the study. We hope to speak to twenty people who developed dementia or mild cognitive impairment while working, members of their families and workplace representatives.

### **What would taking part in the study involve?**

If you are interested in taking part in the study, a member of the research team from the University of the West of Scotland will contact you to tell you more about the project and answer any questions that you may have. If you then decide to take part in the study you will be invited to take part in an interview. A member of the research team will arrange a time that is suitable to meet with. Interviews should last approximately 20 minutes. In order to facilitate note-taking, we would like to record interviews and would seek your permission to do so at the time.

### **What are the benefits or disadvantages in taking part?**

There would be no direct benefit to you from taking part in the project. However, we believe this study will help inform others, support services and employers about the needs and concerns of people with dementia or mild cognitive impairment who are in work, self-employment or have recently left work.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. Participation is entirely voluntary and you would be free to withdraw at any time without giving a reason. Should you wish to withdraw from the study at any time, you may request that anything you have said is excluded from the analysis. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

### **What will happen to information collected in the study?**

All information collected during the course of the study will be kept strictly confidential. Nothing that you say during an interview would be made available to other participants. However, should a participant say anything that has implications for the safety of others, it would be necessary to report this to an appropriate authority, we would discuss this with the participant at the time. No individual will be able to be identified in the study report or any other publication. We may wish to use some word for word quotations to illustrate specific points. Any information used in this way will be anonymised. Audio recordings will be destroyed once they have been transcribed. All participants will be provided with a copy of the final report. The findings will be made available to health and social care professionals, voluntary organisations, employers, and other key stakeholders who are in a position to influence policy and practice relating to

people who develop dementia while in employment or self-employed. The findings will also be presented at conferences and written for publication.

**Further information about this research study:**

Members of the research team will be pleased to answer any question you may have and can be contacted at:

The School of Health, University of the West of Scotland, Hamilton. ML3 0JB

Contact	Telephone	Email
Professor Debbie Tolson	01698 283100	debbie.tolson@uws.ac.uk
Professor Mike Danson	0131 451 3840	M.Danson@hw.ac.uk
Dr Louise Ritchie	01698 283100	louise.ritchie@uws.ac.uk

**Thank you for reading this information sheet.**

## DEMENTIA IN THE WORKPLACE: THE POTENTIAL FOR CONTINUED EMPLOYMENT POST- DIAGNOSIS

### Workplace Participant Consent Form

Participant ID:.....

Date:.....

Principal Researcher: Prof Debbie Tolson

Please initial

I confirm that I have read and understand the information sheet dated 25 <sup>th</sup> April, 2013 (version 2) for the above research study.	
I have had the opportunity to think about the information, ask questions, and have them answered satisfactorily.	
I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason.	
I am happy for interview to be recorded and transcribed, and for verbatim quotations to be used in reports with the understanding that they will be anonymised.	
I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

When completed, 1 for participant: 1 researcher site file (original)

## **DEMENTIA IN THE WORKPLACE: THE POTENTIAL FOR CONTINUED EMPLOYMENT POST- DIAGNOSIS**

### **Case Study Participant Information Sheet**

*(HEALTH OR SOCIAL CARE PROFESSIONALS, STAFF FROM THIRD SECTOR  
ORGANISATIONS E.G. ALZHEIMER SCOTLAND LINK WORKERS, ADVOCACY WORKERS)*

We would like to invite you to take part in a research study. This information sheet provides information about the study and what would be involved if you decide to take part. Before you decide, we would like you to understand why the research is being carried out and what it would involve for you. Take time to think it over, discuss it with workplace colleagues or others. Ask us if there is anything that is not clear or if you would like more information, contact details are included at the end of this document, and a member of the research team would be pleased to discuss the project with you.

### **Who is doing the research?**

The research will be carried out by staff from the University of the West of Scotland who are working with staff from Heriot Watt University, in Edinburgh. The project has the full support of Alzheimer Scotland, the Scottish Dementia Clinical Research Network, and the Alzheimer's Society. The project has been funded by the Alzheimer's Society.

### **What is the study about?**

We are interested in the experiences of people who develop dementia or mild cognitive impairment while in employment. The aim of the project is to find out whether it is possible for people with dementia or mild cognitive impairment (MCI) to remain in employment after diagnosis. We are interested in the experiences of the person who has dementia or mild cognitive impairment, and the challenges faced by employers and co-workers when an employee displays symptoms of dementia, and ways in which they respond to these challenges, as well as the nature and level of support or adjustments that people with dementia or MCI would require to extend their working lives.

**Why have I been invited to take part in the project?**

We hope to speak to twenty people who developed dementia or mild cognitive impairment while working, members of their families and workplace representatives, and health or social care staff who may have supported them. You have been invited to take part in this research because of your role in supporting [name of case study participant], who has a diagnosis of dementia or mild cognitive. [Name of participant] gave us your name and has given us permission to contact you and invite you to take part in the study.

**What would taking part in the study involve?**

If you are interested in taking part in the study, a member of the research team from the University of the West of Scotland will contact you to tell you more about the project and answer any questions that you may have. If you then decide to take part in the study you will be invited to take part in an interview. A member of the research team will arrange a time that is suitable to meet with. Interviews should last approximately 15-20 minutes. In order to facilitate note-taking, we would like to record interviews and would seek your permission to do so at the time.

**What are the benefits or disadvantages in taking part?**

There would be no direct benefit to you from taking part in the project.

**Do I have to take part?**

It is up to you to decide whether or not to take part. Participation is entirely voluntary and you would be free to withdraw at any time without giving a reason. Should you wish to withdraw from the study at any time, you may request that anything you have said is excluded from the analysis. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

**What will happen to information collected in the study?**

All information collected during the course of the study will be kept strictly confidential. Nothing that you say during an interview would be made available to other participants. However, should a participant say anything that has implications for the safety of others, it would be necessary to report this to an appropriate authority, we would discuss this with the participant at the time. No individual will be able to be identified in the study report or any other publication. We may wish to use some word for word quotations to illustrate specific points. Any information used in this way will be anonymised. Audio recordings will be destroyed once they have been transcribed. All participants will be provided with a copy of the final report. The findings will be made available to health and social care professionals, voluntary organisations, employers, and other key stakeholders who are in a position to influence policy and practice relating to

people who develop dementia while in employment or self-employed. The findings will also be presented at conferences and written for publication.

**Further information about this research study:**

Members of the research team will be pleased to answer any question you may have and can be contacted at:

The School of Health, University of the West of Scotland, Hamilton. ML3 0JB

Contact	Telephone	Email
Professor Pauline Banks	01698 283100 Ext 8557	<a href="mailto:pauline.banks@uws.ac.uk">pauline.banks@uws.ac.uk</a>
Professor Mike Danson	0131 451 3840	M.Danson@hw.ac.uk
Professor Debbie Tolson	01698 283100	debbie.tolson@uws.ac.uk
Dr Louise Ritchie	01698283100	louise.ritchie@uws.ac.uk

**Thank you for reading this information sheet.**

## DEMENTIA IN THE WORKPLACE: THE POTENTIAL FOR CONTINUED EMPLOYMENT POST- DIAGNOSIS

### Case Study Participant Consent Form

(HEALTH OR SOCIAL CARE PROFESSIONALS, STAFF FROM THIRD SECTOR  
ORGANISATIONS E.G. ALZHEIMER SCOTLAND LINK WORKERS, ADVOCACY WORKERS)

Participant ID:.....

Date:.....

Principal Researcher: Prof Debbie Tolson

Please initial

I confirm that I have read and understand the information sheet dated 23 <sup>rd</sup> April, 2013 (version 2) for the above research study.	
I have had the opportunity to think about the information, ask questions, and have them answered satisfactorily.	
I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason.	
I am happy for interview to be recorded and transcribed, and for word for word quotations to be used in reports with the understanding that they will be anonymised.	
I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

When completed, 1 for participant: 1 researcher site file (original)



## **DEMENTIA IN THE WORKPLACE: THE POTENTIAL FOR CONTINUED EMPLOYMENT POST- DIAGNOSIS**

### **Relative or Carer Information Sheet** *(RELATIVES OR OTHER INFORMAL CARERS)*

We would like to invite you to take part in a research study. This information sheet provides information about the study and what would be involved if you decide to take part. Before you decide, we would like you to understand why the research is being carried out and what it would involve for you. Take time to think it over, discuss it with family, friends, or other relevant professionals if you wish. Ask us if there is anything that is not clear or if you would like more information, contact details are included at the end of this document, and a member of the research team would be pleased to discuss the project with you.

#### **Who is doing the research?**

The research will be carried out by staff from the University of the West of Scotland who are working with staff from Heriot Watt University, in Edinburgh. The project has the full support of Alzheimer Scotland, the Scottish Dementia Clinical Research Network, and the Alzheimer's Society. The project has been funded by the Alzheimer's Society.

#### **What is the study about?**

We are interested in the experiences of people who develop dementia or mild cognitive impairment while in employment. The aim of the project is to find out whether it is possible for people with dementia or mild cognitive impairment to remain in employment after diagnosis, and if so what support they would need to enable them to do so.

#### **Why have I been invited to take part in the project?**

You have been invited to take part in this research because your [husband/wife/father/mother/parent] has a diagnosis of dementia or mild cognitive impairment, and is in paid employment, self-employed, or left work less than 18 months ago. Your relative already knows about the study and may have mentioned it to you. We hope to speak to twenty families in which

someone has developed dementia or mild cognitive impairment while still working.

### **What would taking part in the study involve?**

If you are interested in taking part in the study, a member of the research team from the University of the West of Scotland will contact you to tell you more about the project and answer any questions that you may have. If you then decide to take part in the study you will be invited to take part in an interview. A member of the research team will arrange a time that is suitable to visit you in your home, or another place of your choice, and ask about your experiences at work. Interviews should last approximately one hour. In order to facilitate note-taking, we would like to record interviews and would seek your permission to do so at the time.

As well as speaking to you about your experiences and perceptions while your [husband/wife/father/mother/parent] was working, we would like to speak to them directly and will also invite them to take part in an interview, either on their own, or with someone else that they know should they prefer.

### **What are the benefits or disadvantages in taking part?**

There would be no direct benefit to you from taking part in the project. However, we believe this study will help inform others, support services and employers about the needs and concerns of people with dementia or mild cognitive impairment who are in work, self-employment or have recently left work.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. Participation is entirely voluntary and you would be free to withdraw at any time without giving a reason; withdrawal would have no impact on any support that your relative is currently receiving. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Should you wish to withdraw from the study at any time, you may request that anything you have said is excluded from the analysis.

### **What will happen to information collected in the study?**

All information collected during the course of the study will be kept strictly confidential. Nothing that you say during an interview would be made available to other participants. No individual will be able to be identified in the study report or any other publication. We may wish to use some word for word quotations to illustrate specific points. Any information used in this way will be anonymised. Audio recordings will be destroyed once they have been transcribed. All participants will be provided with a copy of the final report. The findings will

be made available to health and social care professionals, voluntary organisations, employers, and other key stakeholders who are in a position to influence policy and practice relating to people who develop dementia while in employment or self-employed. The findings will also be presented at conferences and written for publication.

**Further information about this research study:**

Members of the research team will be pleased to answer any question you may have and can be contacted at:

The School of Health, University of the West of Scotland, Hamilton. ML3 0JB

Contact	Telephone	Email
Professor Debbie Tolson	01698 283100	debbie.tolson@uws.ac.uk
Professor Mike Danson	0131 451 3840	M.Danson@hw.ac.uk
Dr Louise Ritchie	01698 283100	louise.ritchie@uws.ac.uk

**Thank you for reading this information sheet.**

# **DEMENTIA IN THE WORKPLACE: THE POTENTIAL FOR CONTINUED EMPLOYMENT POST- DIAGNOSIS**

## **Relative or Carer Consent Form** (RELATIVES OR OTHER INFORMAL CARERS)

Participant ID:.....

Date:.....

Principal Researcher: Prof Debbie Tolson

Please initial

I confirm that I have read and understand the information sheet dated 23rd April, 2013 (version 2) for the above research study.	
I have had the opportunity to think about the information, ask questions, and have them answered satisfactorily.	
I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason.	
I am happy for interview to be recorded and transcribed, and for word for word quotations to be used in reports with the understanding that they will be anonymised.	
I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

When completed, 1 for participant: 1 researcher site file (original)

## 13.6 Identification of other case study participants

## DEMENTIA IN THE WORKPLACE

### Identification of case study participants

The study will involve case studies focusing on a person, aged between 50 and 69, who has been diagnosed with dementia or mild cognitive impairment while still working. In order to gain a real understanding of the potential for people with dementia or MCI to remain in paid employment, we think that it is important to speak to other people, for example other people at work including people you work or worked alongside, employers, representatives from human resources, trade unions, or occupational health. We would also like to speak to family or friends who supported you when your symptoms first developed.

In order to speak to members of your family and/or people that you currently work with, or used to work with, we would like your permission to contact them. If you are willing for us to do this, please provide contact details\* below:

I, ..... (name of participant)

Give permission for research staff working on the above study to contact:

Name of potential participant:.....

Role/relationship:

.....

Address:.....

.....

Telephone:.....

Email: .....

\*If you would rather not give us contact details for someone that you are happy for us to talk to, we can provide information that can be posted directly to them

by you – it would then be up to the person you have nominated to decide whether or not to contact us:

Signature of participant:.....

Name of Researcher:..... Date:.....

Signature:.....

## 13.7 Case study descriptions



# Case study 01

## Part 1 – Background information

<b>Name</b>	John
<b>Age</b>	56
<b>Employment status</b>	Retired
<b>Occupation</b>	Journalist/Lecturer
<b>Date of leaving work (if applicable)</b>	College job – August 2012 Freelance work - July 2013
<b>Diagnosis</b>	Frontotemporal Dementia
<b>Date of diagnosis (approx.)</b>	September 2013
<b>Case study participants</b>	John John's wife John's line manager at the college.
<b>Date of interview</b>	December 2013

## Part 2 – Pen portrait

John is 56 years old and lives with his wife and son. He worked as a freelance journalist and a part-time lecturer in a further education college. Around four years ago, John began to experience some physical problems resulting in his mobility being compromised and he found it difficult to walk long distances and appeared to be unsteady on his feet. He didn't have a specific diagnosis for what was causing this problem, although he was prescribed strong painkillers to help him manage the symptoms. Shortly after the presentation of the physical problems, his wife began to notice that he was becoming more measured in his responses and less able to make simple decisions such as what was for dinner. This was also noticed in his workplace; however both his line manager and his wife had put this down to a side effect of the pain medication he was.

John continued to work despite these problems but began to find working at the college increasingly challenging. He was forgetting to attend meetings at work and not completing admin tasks. This resulted in other staff members stepping in to support John, which often ended with other staff members completing the task for him. His freelance work with newspapers and radio stations was also effected and he was finding that writing articles was taking much longer than it used to, and he was struggling to keep up with conversations when he was on-air John was also aware of these changes in his ability, but like his wife and line manager put it down to changes in his medication and normal ageing.

Throughout this time, John was still attending the hospital for investigations about his physical problems and was eventually referred to a neurologist. After missing a number of appointments, his wife went along to the GP with him to highlight the cognitive problems he was having. Over the period of four years he was misdiagnosed with a range of illnesses before finally being diagnosed with frontotemporal dementia in late summer 2013.

As time went on, the work situation was becoming increasingly difficult for John. He had stopped getting offers of freelance work and although he continued to write his weekly newspaper articles this was becoming more challenging. He had been signed off on sick leave from the college around a year before his diagnosis. While he was on sick leave he was in constant contact with his line manager and the dialogue about whether to return to work had begun. When John received his diagnosis it was decided between him, his line manager and the HR department that it would not be possible for John to continue to work at the college and the process of early retirement through ill health was started. This had just been concluded at the time of John's interview. At the time of his interview, John had no desire to return to work and confessed that he was relieved to have been allowed to leave.

Since John has left work, he has become increasingly withdrawn from his social contacts and activities, and very rarely leaves the house. He still has caring responsibilities for his son, however this is reducing and his wife has to do more of this alongside running her business. She feels increasingly under pressure to work to keep them financially secure and to provide care for John and their son. Overall, John was relieved to leave work as he felt he could no longer cope in that situation and felt he had lost his ambition to do well in his career. John's situation was complicated by the presence of physical symptoms which were the focus of early attempts to diagnose. John being diagnosed with dementia and leaving employment had a negative impact on John, his family and his line manager and colleagues.

## Case study number: 02

### Part 1 – Background information

<b>Name</b>	Joe
<b>Age</b>	52
<b>Employment status</b>	Employed
<b>Occupation</b>	Handy man (previously Joiner)
<b>Date of leaving work (if applicable)</b>	n/a
<b>Diagnosis</b>	Mild cognitive impairment (MCI)
<b>Date of diagnosis (approx.)</b>	2010
<b>Other case study participants</b>	Joe's wife Joe's line manager
<b>Date of interview</b>	January 2014

### Part 2 – Pen portrait

Joe is a 52 year old man who lives with his. He trained as a joiner after leaving school and worked as a foreman on a building site until he was 46. He had an accident at work six years ago which resulted in him going to the doctors and being admitted to hospital where he was initially treated for a stroke. After seeing a consultant and having tests, Joe was told that he had damaged nerves in his neck and this was causing a degree of paralysis on his left hand side. This continued to worsen over the following days and weeks and he lost the use of his left hand. Joe received treatment for his physical difficulties including physiotherapy, occupational therapy and eventually surgery on his hand to correct some of the damage which helped him regain the use of his hand. Joe never returned to his job as a foreman after this incident and was off work sick for almost six years following this while he received treatment.

Over the period of years when Joe was being treated for his physical impairments, he and his family began to notice some signs of memory impairment, such as forgetting to cook the dinner and losing things frequently. They raised this with the doctors on a number of occasions but the focus remained on Joe's physical problems with him being dismissed as too young to have memory problems. However, after more than a year, Joe was referred to a psychiatrist and diagnosed with mild cognitive impairment (MCI). Meanwhile, as his physical symptoms began to improve, Joe started to think about returning to work in some way. His doctors had told him it was not possible for him to return to his old job, however Joe was keen to return to work in some capacity. An advisor at the Job Centre put him in touch with Remploy, who in turn matched him to a job working as a handy man in a local care home. Joe went for an interview and as is standard with Remploy was offered a two week trial. The two week trial was successful and Joe had been working in the care home for nine months at the time of our interview.

Although Joe has memory problems, he employs a number of strategies to overcome these to allow him to carry out his job effectively. He works on a part-time basis, four days a week and travels to and from work by bus. He has a set routine which he follows every day; he goes in and carries out maintenance checks around the care home, checking lights, alarm cords and for anything else that may need attended to. He then goes to the book in the office where all the maintenance requests are logged and begins to work through these marking each one off when he has finished. Finally if all the requests are completed he will carry out other tasks such as touching up paint work in an empty bedroom or clearing out a bedroom for a new resident. He works mainly on his own, with some assistance from the domestic team of the care home.

Joe and his family are happy that he has returned to work and he really enjoys working in the care home. He feels that returning to work has helped him control his symptoms better and he enjoys the challenge and social aspects of his work. His employers are happy with his performance and feel they are in a good position to support Joe to continue working given their knowledge of dementia.

## Case study: 03

### Part 1 – Background information

<b>Name</b>	Michael
<b>Age</b>	50
<b>Employment status</b>	Unemployed
<b>Occupation</b>	Heavy Goods Vehicle (HGV) Driver
<b>Date of leaving work (if applicable)</b>	2011
<b>Diagnosis</b>	Early onset Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	2012
<b>Other case study participants</b>	Michael's wife
<b>Date of interview</b>	February 2014

### Part 2 – Pen portrait

Michael is a 50 year old man who lives with his wife and two children aged 16 and 9. He previously worked as a heavy goods vehicle (HGV) driver for a number of companies, delivering goods to locations around Scotland. Michael had begun to experience symptoms of dementia in his work and found that he had started to get lost more often, did not know how to get to places he had been to many times before and became confused with his paperwork, however he did not have a diagnosis while in work. Michael's wife became worried about him in work as he would often phone her at her work and ask her to phone back with an excuse for him to leave as he felt he could not cope. These phone calls became more frequent and he was sounding increasingly distressed as time progressed. Around this time, Michael was diagnosed with work related stress and depression.

At the time of our interview, Michael was unemployed. He had been made redundant from his job 18 months previously due to the economic situation. After he had been made redundant he got another job as an HGV driver for another company that he had worked for in the past. He only lasted two days in this job as he found it really difficult to learn the new procedures and systems for recording paperwork. He felt he couldn't do the job and the stress related to that was too much for him to take. He also worked as a labourer for a short time but again, he struggled to learn the new tasks related to the job and experienced high levels of stress when working. At this point, Michael had not been diagnosed and a possible diagnosis of dementia had not been considered by Michael, his family or his doctors.

Therefore, Michael was not made redundant as a result of his diagnosis of dementia, however given his diagnosis; he is unable to return to that line of work as all his additional driving licences have been removed. This means he is not able to apply for any jobs in the career he is trained for. The loss of Michael's earnings had a big financial impact on his family as he was the main earner. After he stopped working and was diagnosed with depression, Michael began drinking heavily, which he was hiding from his family. Michael had always taken charge of the family's finances, but when was drinking, he did not pay a

number of bills, including the mortgage. This put the family into further financial difficulties and invalidated their insurance policies. The consequence of this was that when Michael was eventually diagnosed with Alzheimer's disease, the critical illness insurance would not pay out and the family were unable to pay the mortgage. The only way they could continue to live in their house was to sell it back to the council and rent it from the council. This meant the family lost a lot of money which they had paid into the house and now live in their house as a council house. There are a number of other bills outstanding and Michael's wife thinks she may need to declare bankruptcy.

Since his diagnosis, Michael has accessed unemployment benefit and his wife continues to work part-time. They both felt that financially they were 'surviving' compared to a year ago but they still had significant money worries. Michael spoke about wanting to be able to support his family, however not wanting to upset the benefits they now get by going back to work as they can't afford to lose any money, even temporarily. Michael doesn't often go out the house as he has not told many people about his diagnosis and doesn't like to be put in a position where people ask him why he is not working. This has also meant that he has lost contact with a lot of his friends and he doesn't feel that there are any support services available in the area for people his age with dementia. He does receive post diagnostic support from Alzheimer Scotland and he also has a support worker for 2 hours a week who he goes out with. Overall, Michael's diagnosis of dementia and not being able to return to his line of work because of this has resulted in significant financial and social problems for Michael and his family which they feel they have had very little support for.

## Case study: 04

### Part 1 – background information

<b>Name</b>	Jim
<b>Age</b>	66
<b>Employment status</b>	Retired
<b>Occupation</b>	Electrical Engineer
<b>Date of leaving work (if applicable)</b>	Officially retired February 2013 Signed off sick from December 2011
<b>Diagnosis</b>	Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	November 2011
<b>Other case study participants</b>	Jim's wife Company HR representative Company Occupational Health Nurse.
<b>Date of interview</b>	March 2014

### Part 2 – Pen portrait

Jim is a 66 year old man who lives with his wife. He worked as an electrical engineer in a large factory which employed upwards of 1000 people. He worked within the maintenance team who serviced the machinery and electrical equipment within the factory. He began to have some problems in work around 2009 when he was forgetting to finish jobs and carry out the correct paperwork. This escalated over a number of months and on one occasion he left a live electrical panel open on the factory floor while he went for his tea break. His supervisor had previously been covering up for him, however realised at this point that this was a serious problem and referred him to the occupational health nurse. This started a chain of events that led to Jim being diagnosed with Alzheimer's disease in November 2011.

Jim saw the occupational health nurse a number of times over the next month who noticed problems with his memory and also subtle personality changes, such as Jim being more defensive and aggressive at times. After a few appointments, the occupational health nurse phoned Jim's wife to ask how he was in the house. Jim's wife agreed that there was a problem; she had noticed him leaving lights on, cupboards open and also some personality changes. This prompted Jim's wife to make an appointment at the G.P. where he was initially diagnosed with depression and signed off work for three months. When he returned to work, Jim was referred to a company doctor for an assessment on capability to work. The focus was on trying to keep Jim at work, however it was recommended that he was not capable of carrying out a safety critical or mentally challenging role. He was given a job working in the stores of the factory, managing the stock. While he enjoyed this, he struggled to understand why he wasn't allowed to do the job he was being paid for. Throughout this period the company offered Jim other contracts, part-time and at a lower wage, however he turned them down. This led up to Jim's diagnosis in November 2011. At this point, Jim was called to a meeting where the company attempted to terminate his employment on the basis on capability. His union representative, who had attended the meeting, alerted his wife that this was happening and she went to the G.P. who signed Jim off work. Jim never returned to work

from this point until his official retirement on his 65<sup>th</sup> birthday. Under the terms of Jim's employment he was able to claim income protection insurance which allowed him to stay on sick leave until his retirement. This meant that the family were financially secure and that his pension was left to fully mature. Had Jim had his contract terminated at this point it could have had serious financial consequences for his family.

Jim and his wife were interviewed together for this case study as Jim's dementia had progressed and he was not able to fully recount the experience of being in work. This meant that his wife provided the details of the situation and journey to diagnosis and Jim confirmed or added his views when he could. Similarly, in the workplace, the HR representative who was interviewed had been on maternity leave for much of the time that Jim was struggling at work and only returned to work after he was on sick leave so she supported him through the retirement process. The occupational health nurse who had regular contact with Jim throughout the whole time was interviewed with the HR representative to ensure a full workplace perspective.



## Case study 05

### Part 1 – background information

<b>Name</b>	Paul
<b>Age</b>	62
<b>Employment status</b>	Retired due to ill health
<b>Occupation</b>	Council officer (janitorial)
<b>Date of leaving work (if applicable)</b>	April 2013
<b>Diagnosis</b>	Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	2007
<b>Other case study participants</b>	Paul's wife Paul's daughter Paul's line manager Paul's colleague (close friend)
<b>Date of interview</b>	May 2014

### Part 2 – Pen portrait

Paul is a 62 year old man who lives with his wife. He has worked in a number of jobs throughout his career but most recently he was employed as a council officer for a local authority headquarters. He began to experience mild memory problem in his mid-50s which his wife notice very early. She went with him to their GP and he was referred to a psychiatrist and was diagnosed with early onset Alzheimer's disease within 3 months of his initial G.P appointment. At this point, Paul's work had not been affected and he was continuing to work well and hadn't disclosed his diagnosis to his employers. Similarly, his employers or colleagues had not been aware of Paul experiencing any difficulties at work.

Six months after his diagnosis, Paul and his wife took the decision to disclose his diagnosis to his employers. This was mainly because Paul was working night shift which meant he was alone in the building for a large period of time which although there were no incidents, Paul didn't feel comfortable doing this. It was agreed he would continue in his role; however he would only work day shifts. At this point it was agreed that Paul's CPN would leave her contact details and the employers could contact her if they had any questions. Paul continued to work for a number of months with this arrangement with Paul's line manager getting in touch with the CPN when they had questions or problems. However, this form of communication often ended with stories being relayed back to Paul's wife which were incomplete or misinformed. As this was causing distress to Paul's wife, it was decided that regular meetings would be set up between Paul, his employers, his CPN and his daughter to review any changes in Paul's condition and address any problems in the workplace. Meetings were held every 4-6 months. On the back of the meetings a range of supports and reasonable adjustments were put in place to support Paul to continue working. The first of these was the CPN delivering a dementia awareness training session to Paul's line managers and colleagues. This was well received, and helped them to understand the difficulties he was having. Other adjustments which were made for Paul included; standardised tasks so that he

had the same routine and same tasks to carry out for every shift he worked, signage to remind Paul to look for traffic when he went out the back door to take rubbish out. As his dementia progressed, tasks were altered or removed from his routine. One problem that Paul began to have related to his journey to and from work, he was no longer able to drive so he was getting the bus. However, Paul started to become confused and disorientated when using the bus. An occupational therapist recommended that they apply to the Access to Work scheme to provide taxis to take him to and from work. This was successful and he continued to get taxis until he officially retired 18 months later.

Paul worked for six years in total post diagnosis and he really enjoyed working. He had a very good friend whom he worked with, who did all he could to support Paul to continue working. He was mindful of the line between giving support and carrying out the tasks for him though, so he would always try to make sure he could find all the equipment he needed and would help him out if he was struggling with anything rather than covering up for him. Unfortunately, there was some evidence that not all of Paul's colleagues were as supportive as Joe. There was some evidence of workplace bullying and stigma towards Paul. Although Paul's employers were very good at supporting Paul, all the case study participants felt that dealing with his colleagues' attitudes was something that could have been improved.

Paul decided in late 2013 that the time had come to retire from work and that he was satisfied that he had continued to work as long as he could. His employers agreed on this, as adjustments had meant that Paul was only working 2 or 3 days a week at this point as his hours had been gradually reducing. This was good for Paul as it allowed him to phase in his retirement, and by the time he finished work, Paul and his wife were already attending support groups and had other activities in place to fill their time. Paul enjoyed his time working, it gave him a purpose in his life and financial security of working for 6 years post diagnosis until he was in a position he could retire. Paul does miss going to work and the social contact he had with his friend at work. His wife noted that he has lost a lot of motivation since leaving work and is more likely to lie in bed all day as he has no reason to get up. However, Paul and his family are very pleased that he continued to work for so long and accept that as his illness progressed, supporting him was becoming more difficult and he was less able to do his job.

## Case study 06

### Part 1 – background information

<b>Name</b>	Jack
<b>Age</b>	56
<b>Employment status</b>	Employed
<b>Occupation</b>	Telephone engineer
<b>Date of leaving work (if applicable)</b>	n/a
<b>Diagnosis</b>	Frontotemporal dementia
<b>Date of diagnosis (approx.)</b>	2010
<b>Other case study participants</b>	Wife Line manager
<b>Date of interview</b>	May 2014

### Part 2 – Pen portrait

Jack is a 56 year old man who lives with his wife. He works as a telephone engineer for a large company. He has worked as a telephone engineer for 30 years in a variety of roles for the company. He currently works in an office based role as a fibre analyst. This involves assessing reports of faults and issuing instructions to repair them. He really enjoys his job and is well regarded as skilled in many roles within the company.

Jack was diagnosed with Frontotemporal dementia in 2010. The process of getting his diagnosis was not easy and took around 3 years. Throughout this period increasing strain was placed on Jack, his wife and their relationship. Jack was suffering from high levels of stress which resulted in him being signed off his work for a period of time. Jack's wife was becoming increasingly frustrated as she could see changes in her husband that she felt no one else could see which put additional strain on their marriage. This meant that when Jack received his diagnosis, they both felt relieved that they now knew what the problem was and could begin to deal with it.

Immediately after Jack received his diagnosis he informed his line manager. At this point, Jack was managing his job well and there were no issues with his performance so it was decided that Jack would continue to work in this role and support would be provided when he needed it. However, in the following year he had three changes in line manager and his diagnosis was not communicated between managers. This led to a distressing incident where Jack was told that his job was being changed and that he had to start working out on the lines again. Jack's wife phoned his manager and questioned the decision. It was agreed that Jack would continue in the job he was doing and an appointment was made for him with occupational health. Between Jack, his wife, and the nurse they created what's known as a 'Health Passport' for Jack which outlines the problems that Jack has, the adjustments that he needs to continue working and general information about his disability. This is normal practice within his company for anyone who has a disability.

The health passport allows Jack to discuss his disability with his line manager and highlight anything that may be or become an issue for him in his workplace. Since he has had his health passport, he feels well supported at work and has disclosed his diagnosis to his close colleagues who provide support for him when he needs it. Jack's situation however is unusual as although he works in an office, the team he is part of works in offices throughout the country so he has no face to face contact with his team members or line manager. This means that the majority of his communication is carried out through email and telephone. This has been highlighted as a potential issue as his manager may not be able to recognise signs of Jack's dementia progressing easily.

Jack has a number of adjustments to his job and workplace to enable to continue employment. These include keeping his working day to standard hours, addressing Jack's need for routine in his day. He has also been provided with partitions to keep his work area quiet and block out any external distractions. Finally, he has requested that if there are any changes to his job or he is needed to go on training courses then he needs extra time and will require extra support to learn the information. He also has informal arrangements with his colleague that if he gets overwhelmed or stressed at any point in the day he will send him an email explaining this and ask him to cover while he takes 10 minutes away. He feels that the routine of his job also helps him to continue working.

Jack has been working for almost 4 years post diagnosis, and for a number of years before this he was experiencing the symptoms of dementia in his workplace. While continued employment is a positive experience for Jack, he does feel that it is becoming more difficult and he doesn't know how much longer he will be able to work for. He feels that although he can still do his job, it is taking him much longer to complete tasks and he is much more susceptible to stress in his job than he was before. He is also increasingly fatigued at the end of the day. Jack's wife has been a big support for him continuing employment and she sees the benefit of him continuing. However this has had an impact on her health, employment and wellbeing as well. She also worries about the future and how they will cope financially if Jack does have to give up work and if this means she will have to give up work to care for him.

Overall, although there are challenges, Jack continuing to work post diagnosis has allowed him and his family to continue life as normal as much as possible. This is allowing Jack to continue to engage in meaningful activity and means that Jack's wife's journey to becoming his carer is gradual as him continuing to work provides some respite for her as she knows he is safe there. From an employers' perspective Jack's employers are well equipped at dealing with disabilities and although they had no knowledge of dementia, Jack had been well supported under the health passport scheme. Jack's line manager has now taken some dementia awareness training which has helped him to understand more about Jack's condition and think ahead to how to support Jack as his dementia progresses.

## Case study 7

### Part 1 – Background information

<b>Name</b>	Edward
<b>Age</b>	64
<b>Employment status</b>	Retired due to ill health
<b>Occupation</b>	Judge
<b>Date of leaving work (if applicable)</b>	2012 (sick leave since diagnosis)
<b>Diagnosis</b>	Dementia/ small vessel disease
<b>Date of diagnosis (approx.)</b>	2010
<b>Other case study participants</b>	Wife Workplace participants did not respond to invitations for interview.
<b>Date of interview</b>	July 2014

### Part 2 – Pen portrait

#### Overview

Edward is a 64 year old man who has recently remarried and lives with his wife. He started working as a judge in 2001, after training and working as a solicitor. This it was an excellent career move for Edward, however the job was hundreds of miles away and it meant that he had to move away from his family and his partner (now his wife). Following this, Edward and his partner experienced serious relationship problems. At the same time as he was experiencing personal problems Edward began to notice that he was not coping in the workplace in the same way as he had previously. He reported being more susceptible to stress in his job and began to notice memory problems. He found it difficult to follow the flow of a conversation and couldn't remember what was said in meetings, including things he had said himself. This had a direct impact on his ability to argue with people and to make sound judgements in cases, skills which are crucial as a judge.

He reported that his co-workers were aware of the problems he was having with his memory, however he felt this was attributed to other factors such as him getting older and "*being a bit dozy*". His co-workers approach to this was light-hearted and they would commonly joke about his poor memory, indicating that they did not consider this to be a symptom of a more serious problem. Edward felt that his co-workers did support him and in some ways cover up for his problems, for example, they would only give him the information he needed at the time he needed it as they knew he would forget it. Similarly, his wife had also noticed his memory problems, but had attributed this to the stress he had experienced due to the problems in their personal life and did not consider that it could be an indication of a more serious health problem.

As Edward began to struggle more in his job, he went to his GP where he was treated for stress and anxiety. He continued working but his symptoms did not improve. Shortly after

this he had two separate experiences in work where he realised that his problems were impacting seriously on his ability to do his job and he had the potential to cause real problems and have an impact on other people's lives. These events motivated Edward to go back to the GP, and the result of this was his diagnosis of dementia. At the point of diagnosis he was advised by his doctor to inform his employers. He did this and was immediately put on leave until they could obtain a medical report and assessment. Edward went home after that and waited to hear from his employers. He was referred to an occupational health doctor at ATOS who carried out a consultation with Edward over the phone and asked for permission to access his medical records. As a result of this phone consultation and seeing his medical records the occupational health doctor recommended that Edward was no longer fit to practice as a judge. A representative from human resources then phoned Edward 18 months after his diagnosis and informed him of the decision to retire him on the grounds of ill health. Edward was never seen in person by anyone from his work or occupational health service and was not consulted on the decision to retire him, highlighting poor support and management for his situation. This decision left Edward feeling very isolated and unsupported by his employers. It took 18 months from the initial phone call to finalise his retirement.

Financially, although they are comfortable, the premature end of his working life has had an impact on Edward's pension and also his ability to work part-time as a judge after retirement which is often happens. Edward's wife has struggled to come to terms with the changes in Edward's personality and has found him more demanding of her time. This has meant that she has had to change her lifestyle a lot as she has given up the small amount of work she was doing to be with him and is also reluctant to socialise in the same way as they had previously. These changes mean that Edward and his wife have had to change their plans for retirement and alter their lifestyle in order to adjust to their reduced income.

Overall, Edward's diagnosis of dementia resulted in an unplanned end to his working life which left him feeling unsupported by his workplace. This has meant that Edward and his wife have had to alter their retirement plans and living arrangements considerably, with negative outcomes. There are no workplace perspectives in this case study to represent the views of the workplace. Two contacts were provided by Edward however, they did not respond to invitations to participate in an interview. Edward's wife indicated in her interview that Edward's relationship with one of these colleagues had broken down around the same time as he left work, and this may explain why they did not want to participate if the situation and working relationship was not good.

## Case study 8

### Part 1 – background information

<b>Name</b>	Anna
<b>Age</b>	62
<b>Employment status</b>	Retired due to ill health
<b>Occupation</b>	Nurse/Project manager
<b>Date of leaving work (if applicable)</b>	2013
<b>Diagnosis</b>	Early onset Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	2013
<b>Other case study participants</b>	Husband Work colleague/friend
<b>Date of interview</b>	July 2014

### Part 2 – Pen portrait

#### Overview

Anna is a 62 year old woman who lives with her husband and adult son. She has worked as a nurse since she started her training when she was 17. She specialised in children's nursing and over the last few years was recruited to become a project manager working on developing plans for a new children's hospital. The change in job from Senior Nurse to Project manager highlighted a number of difficulties for Anna. She found that she struggled with reading graphs and learning how to use the technology she was required to use. At this point she had good support from her colleague, and they would work together to get the job done, each playing to their strengths. Anna also found that she was having problems with her memory. For example, when she was attending meetings around the hospital she would leave things behind and not realise she had lost them.

As time progressed in her role as project manager, there were some changes in the department with the threat of redundancies. Many of Anna's colleagues left at this point to go to other jobs, including the colleague interviewed as part of the case study. Anna decided to stay in her role as she had worked at the hospital for 40 years and didn't want to leave. However her problems continued and she was given no support in her job but told that she had to improve her performance or she would be put under disciplinary procedures. Job restructuring meant that she had to go through the process of re-applying for her job. This was something Anna found very difficult as she realised she did not have the skills required for the job description. Anna didn't get the job when she re-applied and so it was agreed that she would be made redundant.

Throughout this time, Anna was aware of her difficulties and had attended the GP on a number of occasions concerned about her memory and cognitive abilities. Each time the GP had assessed her and sent her away telling her there was nothing to worry about. Anna was not happy with this and discussed how she suspected that she was developing a form of

dementia because her behaviours had started reminding her of her grandmother who had dementia. Anna's colleague had also noticed changes in her and suspected that it may be due to dementia, although she didn't speak to Anna about these concerns at the time.

After leaving her job, Anna decided that she wanted to continue working and was confident in her skills as a nurse. Therefore, she registered with a nursing agency and started a job working with children with complex health needs in their own homes. In order to start this job, Anna had all her competencies assessed and underwent further training. This helped to increase Anna's confidence after leaving her job in the hospital.

Anna carried on working in this role for a few months and really enjoyed it. She was having difficulties, for example, she was struggling to read medication sheets and couldn't work out where she should sign them. She didn't initially link this to the other difficulties she had been having in her previous job instead blaming it on poor eyesight and poorly designed prescription sheets. However there was one incident which made Anna question her safety to continue practicing as a nurse. Anna had been having difficulty doing simple calculations in her head, and while she was giving a tube feed to a patient she couldn't work out how much more he had to get to finish the feed. At this point she panicked and asked another member of staff to finish the feed for her. She got up and walked into the office and resigned as she knew she wasn't safe to continue. That was the last time Anna worked. After this, Anna went back to the GP and explained her worries and was referred to the local hospital for other tests. Following this, Anna was diagnosed with early onset Alzheimer's disease.

Anna strongly feels that she is still able to live a fulfilling and engaging life, despite her diagnosis. She has a strong family network with her son and husband acting as carers and she has accessed excellent post diagnostic support. Even though she is no longer working, something which she described as "a real wrench" she has made an effort to get involved with a range of activities. Although Anna is no longer in paid employment she has made an effort to continue to engage in meaningful activities where she can use her skills as a nurse, her insight into dementia and be involved in the activities and groups she has always been a member of. Anna feels that doing this keeps her well and has a positive impact on her life and plays an important part in her living well with dementia.

As Anna is now classed as officially retired she is able to claim her pension; she had also got redundancy pay from the hospital they have not been disadvantaged financially from Anna having to stop work earlier than planned. The main effect stopping work has had on Anna was a change in how she viewed herself. She had previously thought of herself as a "natural nurse" and had planned to continue working until she was 70 as she enjoyed her job so much. Now that she is not able to do this, Anna has had to change her view of herself but with the post diagnostic support she has she has been able to find and access meaningful activities which allow her to preserve her identity.

.



## Case study 9

### Part 1 – background information

<b>Name</b>	Rose (interviewed before and after disclosing her diagnosis to employers)
<b>Age</b>	58
<b>Employment status</b>	Employed
<b>Occupation</b>	Team leader
<b>Date of leaving work (if applicable)</b>	n/a
<b>Diagnosis</b>	Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	2014
<b>Other case study participants</b>	Two Daughters Line manager Two colleagues managed by Rose Documents: dementia awareness talk given to team, email to employers disclosing diagnosis.
<b>Date of interview</b>	August/September 2014

### Part 2 – Pen portrait

#### Overview

Rose is a 58 year old lady who lives alone. She works as a team leader within a large organisation and is responsible for the e-rostering team. Her role includes line management of rostering staff, auditing and checking work and providing technical assistance to the larger team on the e-rostering software. Rose describes herself as a workaholic and she really enjoyed working.

Rose suffered a series of mini strokes at the end of 2013, which resulted in her being hospitalised. She was off work for around four weeks and was keen to return to work as she was not comfortable being on sick leave and in her own words *"I don't do sickness"*. She also felt that returning to work helped her recovery more than sitting at home. This highlights Rose's positive attitude to work, which was recognised by all of the case study participants. Her daughter also spoke about how Rose's work was integral to her identity.

Before she had the strokes, Rose had been **aware of a decline** in her short-term memory. She discussed this with her doctors and it was thought that this may be the result of undetected mini strokes Rose had suffered before. When she returned to work Rose continued to notice a decline in her memory and she engaged a number of **strategies to overcome** this, for example, asking staff to send her written requests either by email or post it note, and by using the alarm on her phone for reminders. Her colleagues all noticed this decline in memory and it became a bit of a joke in the workplace.

Over this period, Rose was becoming more and more concerned about her memory loss. She also started experiencing other symptoms such as problems with speech and finding

the correct words, and problems with concentration and multi-tasking. This meant that her speed of working declined and she spent a number of hours in the evening trying to catch up with work to alleviate stress. This had a negative impact on Rose in terms of the levels of stress and fatigue she was experiencing, however she felt that the alternative would be worse.

Throughout this period, Rose was still attending the hospital and seeing a consultant psychiatrist. She received a number of scans and in July 2014 she was diagnosed with Alzheimer's disease. Although she had been prepared for this diagnosis, it still came as a shock for Rose and her daughters. Rose had remained in employment throughout the period of diagnosis and expressed her desire to continue working post diagnosis for as long as she was capable. She had decided that the best way to disclose her diagnosis was by email to her line manager and two close colleagues. She clearly outlined her diagnosis, what aspects of the job she was struggling with and what strategies she was using to overcome these problems. She also outlined her plans for the future, which at this point, was to stay in employment as long as she could by setting herself short term targets and having regularly assessing how well she was coping and performing.

Following her diagnosis, Rose sought support from the Alzheimer's Society and has become engaged with their research network alongside other volunteer roles. This resulted in an attitude change towards her workplace. Rose decided to apply for early retirement and was in the process of doing so at the point of her second interview two months after her diagnosis. The process of applying for early retirement has not been easy for Rose as it is very complex and will take around 7 months. Rose's experience of occupational health was negative; as she found that they had no knowledge of dementia other than the Alzheimer's Society website.

During this period, Rose plans to continue working to the best of her ability and to attempt to train staff so that the technical knowledge she has is not lost when she leaves. This potential loss of knowledge and skills has been a worry for a number of the staff. Since her diagnosis there have been a number of workplace adjustments to support Rose to continue as long as possible. Her working arrangements have changed so that she now works from home two days a week and she is also using up time owed to reduce her working hours. She continues to use the memory aids she had developed pre diagnosis and her colleagues are understanding and supportive of this. Rose has made it known that her preferred form of communication is email and primarily uses this to carry out her routine feedback to staff. While staff are understanding of this, this does cause some workplace problems for her close colleague, who often has other members of staff complaining that Rose's feedback is very harsh.

When she does retire, Rose plans to fill her time with a number of different activities including her volunteer work with the Alzheimer's Society and various groups as well as spending more time with her daughters and friends. All of these will provide Rose with meaningful activities to fill her time and allow her to transition smoothly from full time employment.

## Case study 10

### Part 1 – background information

<b>Name</b>	Chris
<b>Age</b>	55
<b>Employment status</b>	Retired due to ill health
<b>Occupation</b>	Engineer
<b>Date of leaving work (if applicable)</b>	September 2014
<b>Diagnosis</b>	Vascular dementia
<b>Date of diagnosis (approx.)</b>	2010
<b>Other case study participants</b>	Wife Nominated workplace representative did not respond to invitations for interview.
<b>Date of interview</b>	August 2014

### Part 2 – Pen portrait

#### Overview

Chris is a 55 year old man who lives with his wife. He is a mechanical engineer and has worked in a large factory for 19 years. Chris' wife first noticed problems with Chris' speech and memory. He was becoming more forgetful and he was struggling to finish sentences. This prompted Chris to go to the GP. He was referred for a brain scan and shortly afterwards was diagnosed with vascular dementia. This was a quick diagnosis and Chris was put on Aricept and given appropriate support from the local young onset dementia team. Chris has a number of other health problems including, diabetes and kidney disease.

Chris didn't immediately disclose his diagnosis to his employer. Chris loved his job and enjoyed the social aspect of working as well as the technical aspects of the job. He wanted to continue working for as long as possible. He was very good at his job and well respected within the workplace. One of his main roles was to train apprentices and he was very proud of his achievements in that respect. However, as time went on he began to make more mistakes in his workplace and noticed that he was relying more on the procedural manual for tasks which he would carry out every day and as time progressed he had to write down all of his tasks as a memory aid. After a few months, Chris began making more mistakes in his work so he notified his line manager about his diagnosis and although he felt that his manager had little knowledge about dementia, he felt that he was very understanding and supportive. He immediately said that they would do what they could to support Chris to continue working.

A number of adjustments were made to support Chris in his workplace. These included; reducing the work he did training apprentices and increasing his time on machines which had standard operating procedures, which he could follow the manual to carry out without having to rely on his memory. This also reduced the health and safety risk to Chris

and his colleagues as these machines would only operate if the procedure had been followed correctly. Chris decided not to tell his colleagues about his diagnosis, only his line manager and one other colleague knew about his dementia. However, he felt that although they noticed his symptoms they were supportive even though they weren't aware of the cause of his difficulties.

Due to his other health problems, throughout the four years he worked post diagnosis, Chris was off work sick for a number of periods. Working made Chris very tired and as a result of this his health worsened. Chris' shift pattern was changed to shorter shifts and he was given a stool to use when he was at his station so that he didn't need to stand all day. The increased fatigue also had an impact on Chris' journey to work. Chris drove the 25 miles each day to work. Although there were no incidents relating to this, it worried both Chris and his wife as they felt due to the extreme fatigue he suffered, driving may not be a safe option for him. Chris was keen to stress though that he felt his kidney disease had a bigger impact on his performance at work than his dementia and that if he did not have kidney disease, he could have continued employment for much longer than he did.

Following his most recent period of sick leave at the end of 2013, another round of redundancies were announced when Chris returned to work. Chris' wife suggested to him that he might think about taking voluntary redundancy. Chris was not initially happy with this idea as he did not want to lose his job. However, after seeking advice they realised that Chris may be eligible for retirement due to ill health. After speaking this through with Chris and his employers, Chris realised that financially this would be the best option for him and although he was sad about losing his job, he realised that working wasn't helping his health and he had little quality of life outside of his employment as he had no energy to do anything. Chris officially retired in September 2014 and although he misses his work and his workmates, he feels that his health has benefited and that leaving work has greatly reduced his stress levels.

Financially, Chris and his wife are comfortable now that he has retired. They have paid off their mortgage and can live off Chris' pension and his wife's salary. Chris has begun to develop new interests, for example gardening and would like to revisit old ones like fishing. Chris has attended dementia support groups but feels he cannot identify with the people in these groups as they are all older than him and their dementia has progressed further so communicating is a challenge. This means that Chris spends a lot of his time at home and misses the social contact from his workmates. This also has an impact on Chris' wife as she worried about him being alone in the house so she has changed her working arrangements so that she can work from home more often.

In Chris' case, a number of his problems at work stemmed from his other health issues and he feels that he could have continued working if he was only dealing with dementia. Leaving work has been a positive outcome for Chris as he has control over his decision to leave, is comfortable financially and feels that his health has improved as a result. Chris had provided his line managers' contact details for the case study, but unfortunately he did not respond to invitations for an interview.

## Case study 11

### Part 1 – background information

<b>Name</b>	Tom
<b>Age</b>	62
<b>Employment status</b>	Unemployed
<b>Occupation</b>	Projectionist
<b>Date of leaving work (if applicable)</b>	Made redundant in December 2013
<b>Diagnosis</b>	Cortical basal degeneration
<b>Date of diagnosis (approx.)</b>	1999
<b>Other case study participants</b>	Wife Line manager
<b>Date of interview</b>	September 2014

### Part 2 – Pen portrait

#### Background

Tom is a 62 year old man who lives with his wife. In 1999, he was diagnosed with a rare form of dementia called cortical-basal degeneration and at the point of diagnosis was given approximately two years to live and told he could no longer work or drive. At this point, Tom left his job as a trades officer in the prison service. After a few years of not working, Tom realised his symptoms were not declining at the predicted rate and he was managing his symptoms well.

In the years following his diagnosis, Tom attended to various day centres and dementia support groups. He was encouraged by his wife to stay active and attended a day centre for adults with mental health problems which he enjoyed more than the dementia groups. The day centre closed down due to a lack of funding in 2004 and Tom then started to think about returning to work as he felt that he was managing his symptoms and wasn't getting the stimulation he required attending the dementia day centre. At this point he applied for a job he saw advertised in the newspaper for a projectionist in a new cinema. Given his previous technical skills, he got the job and worked there for 9 years before being made redundant at the end of 2013.

When Tom started work, he was assessed by occupational health to check if any adjustments would be required to allow him to carry out his role. The main adjustments that were put in place related to his physical symptoms and included policies to ensure Tom's safety on the staircase up to the projection room and to make sure he wasn't carrying heavy film reels up and down the stairs. Tom's job had a set routine, which he followed everyday he came into work. He received training on how the equipment worked and because of his technical skills background he picked it up reasonably quickly. This meant that he could easily follow the procedure to play films and fix any problems with the projector.

Tom worked on a casual basis at the cinema for 9 years. Throughout that time he worked a range of shifts and varied hours per week. After a few years he was given a contract for 3 hours per week which meant he was guaranteed one shift a week, however he always worked more hours than this. Tom's line manager felt that over the period Tom worked there his performance in his job did not decline and he was confident in his ability. Tom was reviewed on a regular basis and his line manager felt that he had the support of the company in supporting Tom in his employment.

Tom did face some problems in his work, for example on a couple of occasions he reported that he played the wrong film. However he also was quick to notice his error and rectify it. Overall though Tom and his line manager both felt that Tom was good at his job and did not cause any more problems for his line manager to deal with than any other employee.

The cinema was renovated towards the end of Tom's employment there and part of this renovation was to move from analogue projectors to digital projectors. These new projectors were semi-automated so didn't need the constant attention of a projectionist when a film was showing. This meant that the role of projectionist in the cinema changed and all the current projectionists were made redundant. New jobs were advertised which had a slightly different job description and involved some customer service work within the café at times when the film was running. Tom and another person applied for this job however, Tom was not successful in his application. This meant that when Tom was made redundant in 2013 he was no longer in paid employment, however he still feels he would like to continue working in some way.

Tom really enjoyed his job at the cinema and found that there were many benefits from him working beyond the financial rewards. He enjoyed the social contact, felt that it helped him to increase his confidence and build his sense of identity. Tom and his wife both agreed that he didn't need to work as they had enough money to get by so it meant that his income from the cinema was an extra and allowed him to buy treats for himself and the family if he wanted to. However, leaving work has been a difficult process for Tom, he feels that the process of him leaving was not fair and he has been left humiliated after having to reapply for the job and not getting it. His line manager had a different view of the process; he spoke of how the recruitment process was very difficult for him to conduct. He also was aware of how much the job meant to Tom and felt that that may have contributed to him getting down to the last two in the recruitment process more than the skills he had for the job.

However, where other people got offered alternative roles in other theatres or cinemas, Tom did not and this influenced his thoughts about being pushed out and unfairly treated. Tom is still keen to return to work, however he is now struggling to find a job which may be suitable for him which will let him use his skills and technical knowledge.

## Case study 12

### Part 1 – Background information

<b>Name</b>	Ken
<b>Age</b>	62
<b>Employment status</b>	Employed
<b>Occupation</b>	Shop keeper (family business)
<b>Date of leaving work (if applicable)</b>	n/a
<b>Diagnosis</b>	Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	2008
<b>Other case study participants</b>	Wife Brother and sister in law (co-owners of the shop).
<b>Date of interview</b>	October 2014

### Part 2 – Pen portrait

Ken is a 62 year old man who lives with his wife and three teenage children. He owns a mini retail store which sells a variety of items from food and drink to clothes and household goods. This is a family business which he runs with his brother and previously his father. Ken was previously responsible for much of the running of the shop including ordering and dealing with suppliers, managing staff and selling goods. A few years before Ken's diagnosis in 2008, his brother began to notice that Ken was making more mistakes, forgetting to pass on messages and carry out routine tasks. Another early symptom that Ken experienced was having trouble with money and doing calculations which caused him problems in the workplace. These difficulties along with other problems that he was experiencing when driving and at home prompted Ken to go to the doctors. After his initial visit to the doctor Ken spoke to his wife about his concerns and the fact that the doctor had referred him to a neurologist. They made the decision to use their private health insurance and went to see a neurologist privately who carried out a number of scans and tests before diagnosing Ken with early onset Alzheimer's disease.

Although Ken received a quick diagnosis, the post diagnostic care he received was not good and although Ken was relieved to have the diagnosis as it meant that he could explain why he was having these problems it left him and his wife unsure what the prognosis was and how to access the appropriate support. Ken, his wife, and his brother were all keen for Ken to continue working for as long as was possible. Ken continued going to work and his brother adjusted his duties as required. Initially there were little changes required and these just involved taking some of the responsibility away from Ken but keeping him working day to day in the shop. As Ken's dementia has progressed, he has lost many of his skills and his brother has had to ensure that there is adequate staffing in the shop to cover the business needs but to also provide support to Ken while he is there. This has direct costs on the business, however, Ken's brother is happy to absorb these costs as he feels the value Ken gets from coming to work every day is more important. Similarly, Ken's brother is keen to keep Ken doing routine jobs within the shop as he feel that if he takes work away from Ken then

he quickly loses the skills and declines quicker. Again, this may be at a cost to the business but he is happy to absorb this for the benefit of keeping his brother well.

Ken's situation is unusual in terms of the other case studies as he works within a family business. This means that Ken's brother has to balance supporting his brother, but also running a successful business. Although he admits if Ken wasn't his brother he would not have been able to continue to support a staff member for as long as he has, he does recognise that Ken does still have a function within the shop, however diminished.

Ken and his brother have come to the decision that they will sell the business. Ken's brother's worry is that if he has health problems he will not have anyone to support him to run the shop and that now would be the best time to get out and enjoy his retirement. He is unsure how long Ken will be able to continue at work but has said that as long as he still wants to continue working then he will do all he can to support him.

Continuing working has been beneficial for Ken in a number of ways, all of his family feel that continuing with the routine of getting up and going to work each day help to maintain some of his functioning. Although he is unable to do the majority of tasks in the shop he still interacts with customers and will explain to them he has Alzheimer's disease if he cannot help them and get someone else to help. He enjoys this contact and a number of his customers are regular customers who he has known for many years. Ken also continues to travel to work himself every day using the bus which helps him retain his independence and his confidence in doing so. Although his wife is worried about how long he will be able to sustain this especially throughout the dark nights of winter. Ken is very tired after working a shift in the shop, however his family also believe that this is to do with his medication which disrupts his sleep leaving him more tired through the day as well.

Ken and his wife have three children who are still at school and university. This means that Ken's wife has a number of caring responsibilities for the children as well as Ken and she is happy that Ken has continued working as long as he is able. This means that she does not have to worry about him during the day and she gets some respite from her caring role when he is at work as she knows he is safe and looked after. Financially, the family don't have any serious concerns, if Ken was to stop working his wife is confident they would be financially secure because they have paid off the mortgage and they could survive on her income from her pension.

Overall, Ken has continued working for almost six years post diagnosis. Although there are some challenges associated with supporting Ken, especially relating to the running of his family business, his family are all in agreement that the benefits associated with Ken's continued employment much outweigh the financial costs of supporting him. Ken enjoys going to work and appears to benefit from the routine and social contact he experiences by continuing to work.



## Case study 13

### Part 1 – background information

<b>Name</b>	Joan
<b>Age</b>	55
<b>Employment status</b>	Employed
<b>Occupation</b>	Head of Business Development and Support
<b>Date of leaving work (if applicable)</b>	
<b>Diagnosis</b>	Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	2012
<b>Other case study participants</b>	Husband Line manager Employee (line managed by Joan)
<b>Date of interview</b>	October 2014

### Part 2- Pen Portrait

Joan is a 58 year old woman who lives with her husband. She works as the Head of Business Development and Support for a small organisation (around 30 employees). She was diagnosed with Alzheimer's disease in 2012 after attending the GP with concerns about her memory a number of times for almost 10 years previous to this. Joan continues to work full time following her diagnosis with minimal adjustments to her job role and working conditions.

Joan reports that she first noticed changes in her cognition in her early 40s. These were small changes to her memory such as having to refer to notes and minutes. Joan has worked full time in her current role as Head of Business Development and Support for almost 10 years. She was line manager for the majority of the team as well as responsible for the company's finances and human resources as well as sourcing new business.

Throughout the next two years, Joan felt that she had a further decline and decision making was becoming increasingly difficult and her confidence in her work was affected. She experienced further problems in her work with her memory, for example not being able to remember what she had said to staff members in disciplinary meetings and although she was still completing her work, it was taking longer and longer to do it. The trigger for her returning to the GP again was meeting a man with whom she had had a two hour meeting with two weeks previously and not being able to recognise him when he came over to say hello. The doctor she saw listened to her concerns and referred her to the memory clinic for further tests. Joan has a very high IQ and was previously a member of Mensa, so she did very well on most of the tests indicating no cause for concern even though Joan was aware of a decline herself. However, she did have problems with the memory test which resulted in her being referred for MRI scans which led to Joan being diagnosed with Alzheimer's disease in 2012.

Throughout this time, neither Joan's employer nor husband knew that she was concerned about her memory and cognition and she only told them about it once she had her diagnosis. All of the other informants in the case study reported that they had perhaps been aware that Joan's memory was not great, but they had not noticed any of the other problems that Joan had been experiencing and were all very shocked to hear her diagnosis. Joan told her line manager, the director of the company about her diagnosis immediately after receiving it. His reaction, although shocked, was positive in trying to understand more about dementia and work with Joan to create a plan to support her to continue working in her role as long as possible. Joan and her manager have a very open and honest relationship and they spoke frankly about her role and how long she would be able to continue.

As a result of this, a few changes were made to Joan's job description. She would no longer be line manager for the majority of staff, just the staff she worked closely with on her team (3 people) and she would focus on the business support side of her role, rather than business development. The staff on her team were given more responsibilities and Joan's role was to help to upskill the staff to limit the loss of Joan's skills to the business, when and if she did decide to leave. Joan's and her team's salaries were all adjusted to reflect the changing responsibilities.

Joan found that the Alzheimer's medication she was prescribed made her feel very ill so she stopped taking it. She then started taking high dosage vitamin B supplements after reading a research paper about the possible benefits in Alzheimer's disease. This meant that Joan felt much more able to continue working and her line manager and husband both saw a perceptible improvement in Joan's symptoms. Initially, Joan only told her close colleagues in her team about her diagnosis so that they could understand why the changes were happening. The team member spoke about how this was a bit difficult as she felt that she had to defend Joan to other members of staff if she had forgotten to do something. She was relieved when Joan made the decision to disclose her diagnosis to the whole team.

Joan is now taking longer to complete her work and although she has arranged to do condensed hours over four days; she does now work the fifth day at home to keep on top of her workload. This has impacted on the time she has to spend with her husband and engage in other social activities. Although Joan's confidence has been affected and she admitted she did tend to avoid social engagements following her diagnosis. Joan has no plans to stop work in the near future as she feels that it is benefitting her to do so, both financially and for her wellbeing. She also feels that having the routine and challenge of work benefits her greatly and allows her to control her symptoms more than if she retired. In the back of her mind though is the thought that she doesn't know what the speed of decline may be for her dementia and she would like to be able to stop working in order to spend quality time with her husband as well. This also has implications for when she would like to take her pension.

## Case study 14

### Part 1 – Background information

<b>Name</b>	Mary
<b>Age</b>	55
<b>Employment status</b>	Retired due to ill health
<b>Occupation</b>	Office Manager
<b>Date of leaving work (if applicable)</b>	2014
<b>Diagnosis</b>	Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	2013
<b>Other case study participants</b>	Psychologist Mary did not feel comfortable including a family member or a workplace contact in the study as the situation was very upsetting.
<b>Date of interview</b>	March 2015

### Part 2 – Pen portrait

Mary is a 55 year old woman who has worked as an office manager for a small company for the last 28 years. She was responsible for the office administration, finance and human resources within the company. She also line managed a team of about 10 staff. In 2013, Mary began to experience symptoms which affected her work. She began to make more mistakes in work and suffered from high levels of stress. She went to the doctors at this point and her difficulties were attributed to the menopause and that she was experiencing difficult family circumstances which were causing a lot of stress for Mary. Mary was put on sick leave at this point for a couple of weeks before returning to work.

Her problems did not improve any and she then began to make more serious mistakes. She had been called into a meeting after making an error with the finances for the company and suffered a panic attack. At this point, the company referred her to occupational health and she also went back to her doctor. Occupational health did an assessment and told her that she was no longer fit for work and she was put on long term sick leave. Mary's GP had referred her for further tests and she continued to have contact with occupational health and her workplace.

Following a number of delays, Mary was diagnosed with Alzheimer's disease in 2014. Mary informed her work of her diagnosis and was told she would never work again and her employment was terminated. This left Mary feeling incredibly let down by her employers and she felt that she was not given any support that she was entitled to. This was the last contact Mary had from her workplace.

Since Mary left work in 2014 she has had no financial support or benefits, meaning that she has to rely on family to support her financially. At the point of interview Mary was being assessed for a Personal Independence Payment (PIP) however, her first application had been turned down and she was very nervous about going through the system again. Mary is

being supported by the Jobcentre and her healthcare professionals since she has left work. However, they have identified that she is struggling to deal with the paperwork associated with benefits claims and she is unsure of her position with regards to her future financial situation regarding her pension etc.

Overall, Mary feels like she has had very poor support surrounding her employment and this has had a negative effect on her wellbeing. She feels she has lost much of her social network after she left work and she feels very let down and upset by the treatment she got in her workplace. This has impacted on her confidence and her sense of identity. She feels that she is left in limbo until she can sort out the financial aspects of her life.

Mary did not feel comfortable including a workplace representative in the case study given the nature of the situation. Although she is still in touch with one of her colleagues, she felt that asking her to participate would put her in an awkward situation and perhaps be a conflict of interests given that she still works for the organisation. Similarly, Mary's home life has been in turmoil following her diagnosis and Mary and her husband have recently separated. Mary did not feel she could ask him to participate in the study as they were only just starting to rebuild their relationship.

## Case study 15

### Part 1 – Background information

<b>Name</b>	Alison
<b>Age</b>	52
<b>Employment status</b>	On sick leave (will retire 27 <sup>th</sup> July)
<b>Occupation</b>	Maternity Care Assistant
<b>Date of leaving work (if applicable)</b>	2014
<b>Diagnosis</b>	Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	2014
<b>Other case study participants</b>	Husband Dementia nurse Work colleague

### Part 2 – Pen portrait

#### Overview

Alison is a 52 year old woman who lives with her husband. She has worked as a maternity care assistant for the past 10 years. This job involved assisting midwives to deliver babies, supporting mothers with breastfeeding and the daily running of the labour and post-natal wards. In 2013, Alison suffered a bereavement which led to her being off work for a period of six months. When she returned to work in early 2014, her colleagues noticed her performance at work was not at the same standard as it had been previously. Alison struggled to learn the new patient management software which had been installed when she was off sick, and her colleagues noticed that she was becoming increasingly forgetful when she was asked to carry out a task.

Alison's close work colleague also noticed some more subtle differences in Alison's behaviour such as she began to shuffle her feet and was not as confident as she had been before. Alison was taking much longer to carry out tasks and was not viewed as a reliable member of staff within the unit. Initially, this was put down to the bereavement Alison had suffered. However, no one ever spoke to Alison about her performance at this point, rather the midwives in the unit were instructed to observe Alison's work and record her performance on each shift she was on without Alison knowing. This indicates that Alison's colleagues were aware of her problems in the workplace; however there were no efforts to support her to improve her performance.

Alison went to the doctors in July 2014 and decided following initial tests that it wasn't safe for her to return to work at this point so she was signed off sick. Alison found that going to work was stressful as she was being monitored and as she had such a safety critical role, the stress of worrying that she might make a mistake was further impacting on her performance at work.

Alison then underwent a period of testing and scans before she was diagnosed with early onset Alzheimer's disease in December 2014. Waiting for a diagnosis was a source of frustration for Alison and her husband, and they struggled to understand why there was so much of a delay in getting the diagnosis. When Alison received her diagnosis, she informed her employers and was called in for a meeting with occupational health and human resources. At this point, Alison was given three options for her employment, early retirement, retirement due to ill health or redeployment to a non-safety critical role. It was agreed that it was not possible for Alison to return to her previous role as maternity care assistant. Around this point, Alison was referred to a post diagnostic support service and an occupational therapist. The occupational therapist reported back to Alison's employers on the skills that Alison has retained and the type of role she may be able to do. However, at this point, the process with her employers had been going on for a number of months and was affecting Alison's mental health. Alison felt that she had lost control of the situation and she decided to take early retirement to take the decision out of her employers hands.

Alison's view of the situation is that she was treated fairly by her employers. However, all of the other case study informants agreed that her employers did not do everything they could to support Alison and have let her down. In particular, Alison's husband felt that although the option of redeployment was given, there was never any discussion of how that might be put in place and they seemed focused on pushing Alison towards retirement. Similarly, Alison's colleague felt that when Alison was in work, she wasn't treated fairly and she is now struggling to come to terms with the fact that her employer and colleagues would treat an employee in that way. This is having an impact on her feelings towards her work and job satisfaction.

Since Alison has stopped working, and has now made the decision to retire, she feels much happier in herself and feels that the symptoms of dementia have improved. Similarly, her support nurse and husband have noticed a difference in her wellbeing since making the decision. The decision itself was not an easy one for Alison and she does find it difficult to talk about leaving work. She is unsure what the future will hold for her and feels like she is unable to make any decisions on this until she reaches her final retirement date at the end of July.

Overall, Alison has had a difficult experience in her workplace as a result of being diagnosed with dementia. Although she is happy with her decision to retire from work and accepted that she was unable to continue working in her role, this has been the result of a number of months of uncertainty and further stress and anxiety. Alison's situation in the workplace has been a source of stress for her family and her work colleague who have all struggled to see the way that Alison was treated by her employers.

## Case study 16

### Part 1 – Background information

<b>Name</b>	Myra
<b>Age</b>	53
<b>Employment status</b>	On sick leave
<b>Occupation</b>	Office manager
<b>Date of leaving work (if applicable)</b>	2014
<b>Diagnosis</b>	Alzheimer's disease
<b>Date of diagnosis (approx.)</b>	2014
<b>Other case study participants</b>	Husband Line manager

### Part 2 – Pen portrait

Myra is a 53 year old woman who lives with her husband and their three grown up children. She has worked as an office manager in a school for 12 years. Her main duties were ordering supplies for the school, dealing with children and parents in the office and supervising the other office staff. About two years ago, Myra began to have difficulty carrying out her job. She found she was forgetting to do a lot of tasks or forgetting how to use systems and she was increasingly suffering from the effects of stress. This continued for a couple of months until the head teacher of the school questioned why there was so many mistakes happening. Myra visited her GP to discuss her problems and was told that her memory problems were linked to the menopause.

Myra continued working, which she was finding increasingly difficult and was becoming more stressed in her workplace. The head teacher of the school had recently started and Myra blamed the difficulties she was having on the head teacher's different approach to running the school and the fact that she had to learn new procedures and adapt to her style of working. On one occasion, work got too much for Myra and she walked out of the office in the middle of the day leaving the keys on the desk and saying 'I can't take any more of this'. Myra attended the GP again and was signed off work with work-related stress for a month. The head teacher of the school found this situation very difficult to deal with as she did not know Myra before she began having problems in work so did not see a decline in her performance from her previous competent abilities. The head teacher attempted to support Myra as much as possible; although this got to the stage that she felt that she was doing the job of office manager as well as being head teacher. This had a negative impact on the head teacher too as the stress she was under begun to impact on her health.

Myra returned to work after being off sick for a number of weeks and the situation continued to deteriorate. There was then a serious incident involving Myra, when a child reported she had given him medication which she was not authorised to do so. This led to the local authority starting disciplinary procedures against Myra. This was a very stressful time for Myra and again she was signed off sick with work related stress. However, this time she

was referred to further tests for her memory and she was diagnosed with Alzheimer's disease around 10 months after Myra stopped working. Throughout this time, Myra was having regular meetings with human resources and the head teacher. At this point, it was accepted that Myra's problems were not related to the menopause but waiting for the diagnosis meant that the process has been drawn out. As soon as they received the diagnosis Myra and her husband informed her employers and the disciplinary procedure against her was dropped. It was accepted that Myra was not able to return to her previous role and she was given the option of taking early retirement. Myra and her husband both agreed that Myra's symptoms improved as soon as the stress of continuing work had been removed and decided that early retirement would be a good idea. Myra's husband said that redeployment to another role had been discussed at one point, although he got the impression they would much prefer for her to take retirement.

Myra is now in the process of applying for early retirement and they are waiting to hear about the decision of whether to grant tier 1 or tier 2 pension. This process has been ongoing for a number of months, and whilst Myra feels that since she has had her diagnosis her employers have been supportive, she also feels like she is left in limbo waiting for their final decision. This has stopped Myra being able to make plans for the future such as whether she might like to find another job (voluntary or paid) which she could do. However, Myra's confidence in her abilities appears to be diminished so she feels like there is not a lot she can do because of her memory impairment. Myra hopes that her retirement decision will be made in the next month or so and then she feels like she will be in a position to make plans for what to do.



## Case study 17

### Part 1 – Background information

<b>Name</b>	Phil
<b>Age</b>	56
<b>Employment status</b>	Retired
<b>Occupation</b>	Off shore safety inspector
<b>Date of leaving work (if applicable)</b>	2015
<b>Diagnosis</b>	Frontotemporal dementia
<b>Date of diagnosis (approx.)</b>	2015
<b>Other case study participants</b>	Wife

### Part 2 – Pen portrait

Phil is a 56 year old man who lives with his partner. He worked as an off-shore safety inspector specialising in coating and insulation. Phil was diagnosed with frontotemporal dementia in January 2015 and his doctor advised him it was no longer safe for him to continue working. Phil and his partner then took the decision for him to retire from work.

Phil was not aware that his performance at work was compromised as a result of his dementia. He felt able to continue to inspect paint work and assess its safety. However, his partner pointed out that what he struggled with was translating the knowledge he had about his inspections into the required reports. She found that he started to come back from his two week period off shore with a stack of unfinished reports which she had to sit down with him and help to complete. For about two years previous to this, she had begun to notice changes in Phil's personality and behaviours which concerned her. She went with him to the GP on a number of occasions and each time the symptoms were explained by something else, for example, another health problem, or that they perhaps were just not compatible as a couple. This went on for a number of months, with Phil's partner continuing to notice a changes in his abilities. She then realised that he was avoiding going to work, or he was coming back from off shore unscheduled and not telling anyone he was home. Around this point, she also found out about a serious issue relating to Phil's behaviour in the workplace. She went back to the GP with Phil and he was referred to a specialist. As Phil's partner had private healthcare they then went to a private neurologist and psychiatrist to get a diagnosis. This meant that Phil was diagnosed within a month of attending the GP and at this point he was advised not to continue working in his current safety critical role.

Once they had a diagnosis, Phil's partner phoned his line manager to tell him about the diagnosis. He had said they were aware that something was wrong with Phil, although they didn't realise the severity of it. It had been recognised that Phil's reports were not up to standard, however his colleagues had protected him by hiding these issues from higher management and fixing his reports for him to make sure they were up to standard. It was important that as well as completing an accurate inspection of completed work that the report

was completed properly for insurance purposes. This was done in order to protect Phil from any future repercussions. The diagnosis helped to explain the problems Phil had in his workplace and his line manager then supported him to retire from employment. This was done again without informing any senior management of his diagnosis, instead as Phil was a self-employed contractor he submitted a letter informing them of his decision.

As Phil was not aware of his diminished ability to complete his job, he believes that he has stopped working purely because of financial problems in the oil industry which resulted in his daily rate of pay being cut by 15%. Phil is currently not involved in any further work, although he has still been getting offers of work based on his reputation within the field. He is adjusting to being retired, however he is still in the process of deciding if there are any other activities he might like to be involved in. He is being supported by Alzheimer Scotland to do this. Phil's partner is also adapting to having him back full time in the house and her role as carer. Her employers have not been considerate to her needs as a carer and have not allowed her any time off to support Phil at appointments. This means she has to use her holiday allocation to support Phil when he needs it and her situation with her employer is not good, but she feels she needs to continue working as hers is the only salary coming in to the house now.

Phil had given his permission for his line manager to take part in the study. However after initially agreeing to an interview, it proved difficult to schedule a time and two appointments were cancelled after which he never responded to further contact made.